NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

HEALTH AND SOCIAL CARE DIRECTORATE

QUALITY STANDARD CONSULTATION

SUMMARY REPORT

1 Quality standard title

Eating disorders

Date of quality standards advisory committee post-consultation meeting:
20 June 2018 (30 minute session)

2 Introduction

The draft quality standard for Eating disorders was made available on the NICE website for a second 4-week public consultation period between 12 March and 9 April 2018. Registered stakeholders were notified by email and invited to submit consultation comments on the draft quality standard. They were advised that a second consultation was being undertaken to seek comments on the new statements suggested by the committee following feedback from stakeholders. They were asked to focus comments on the new areas (statements 1, 5 and 6).

Comments were received from 20 organisations, which included service providers, national organisations, professional bodies and others.

This report provides the quality standards advisory committee with a high-level summary of the consultation comments that are relevant to statements 1, 5 and 6 prepared by the NICE quality standards team.

Consultation comments that may result in changes to the quality standard have been highlighted within this report. Comments suggesting changes that are outside of the process have not been included in this summary. The types of comments typically not included are those relating to source guidance recommendations and suggestions for non-accredited source guidance, requests to broaden statements out of scope, requests to include thresholds, targets, large volumes of supporting information, general comments on the role and purpose of quality standards and requests to change NICE templates. However, the committee should read this summary alongside the full set of consultation comments, which are provided in appendix 1.

3 Questions for consultation

Stakeholders were invited to respond to the following general questions:

1. Does this draft quality standard accurately reflect the key areas for quality improvement?

2. Are local systems and structures in place to collect data for the proposed quality measures? If not, how feasible would it be to be for these to be put in place?

3. Do you think each of the statements in this draft quality standard would be achievable by local services given the net resources needed to deliver them? Please describe any resource requirements that you think would be necessary for any statement. Please describe any potential cost savings or opportunities for disinvestment.

Stakeholders were also invited to respond to the following statement specific questions:

1. For draft quality statement 1: For children and young people we have used the referral to assessment and treatment times as stated in the Access and waiting time standard for children and young people with an eating disorder: commissioning guide (NHS England, 2015). Are these referral to assessment and treatment times also achievable for adults? Please detail your answer.

4 General comments

The following is a summary of general (non-statement-specific) comments on the quality standard.

- The new statements were supported for having potential cost savings through improved recovery rates and reduced subsequent use of healthcare services (in particular reduced inpatient admissions).
- Stakeholders suggested including references to dentistry in statements 1 to 5.

Consultation comments on data collection

- Statement 1- Diagnostic information recorded on local systems was reported as being inconsistent.
- Statement 1- Data collection is feasible and generally well established. However, the mental health dataset (MHDS) will need clarification and amendment to reflect the complexity of treatment provided in CAMHS eating disorder services and the Eating disorders: recognition and treatment (2017) NICE guideline NG69.
- Statement 1-The outcome measures on recovery and relapse rates may be difficult to measure.
- Statement 5- Collecting information about joint care plans for local audits of patient records will be extremely time-consuming unless specific resources are made available. Following up on relapse will be even more difficult.
- Statement 6- The completion of risk assessments would be accessible via electronic record keeping systems. However, this will not indicate the assessment’s quality.
- Qualitative data from service users, their parents and carers (if appropriate) and health professionals should be collected to help monitor the implementation of these quality statements.

Consultation comments on resource impact

- The achievement of the new quality statements is largely dependent on sufficient funding, workforce and training being provided to eating disorder services and other relevant services.

- Statement 1- Current resource limitations for eating disorder services for adults were specifically raised with stakeholders highlighting that they are significantly underfunded.

5 Summary of consultation feedback by draft statement

5.1 Draft statement 1

People with suspected eating disorders who are referred to an eating disorder service start assessment and treatment at the earliest opportunity.

Consultation comments

Stakeholders made the following comments in relation to draft statement 1:

- The waiting time starts at referral to start of treatment not assessment. Referral to start of assessment is not a current set standard for monitoring.
- Include people who self-refer and adults who are referred to non-specialised adult mental health services in the statement's population as not all areas have local adult eating disorder services.
- The statement's timeframe of 'earliest opportunity' is vague.
- Concerns were raised about referrals being rejected due to service capacity and it was also highlighted that referral information can be inconsistent.
- Focus should be on the individual and not on the services available.
- Add risk assessment to this statement or title and include details on risk assessment from The Royal College of Psychiatrists' reports- MARSIPAN: Management of really sick patients with anorexia nervosa (2014) and Junior MARSIPAN: Management of really sick patients under 18 with anorexia nervosa (2012)
- Definitions are needed for the classifications of high risk, urgent and non-urgent cases.
- Add the significant impact of undiagnosed and untreated eating disorders on individuals, their families, the health sector and wider UK economy to the statement's rationale.

- The statement should highlight how IBD in this group could be eliminated.
- There was a suggestion to make this a developmental statement.
- With regards to equality and diversity considerations neurodevelopmental conditions such as autism need to be considered during assessment and access for people with suspected eating disorders.

Consultation question 4

Stakeholders made the following comments in relation to consultation question 4:

- Overall agreement in principle but quality standards must be achievable within the current system and funding available. The waiting time to treatment for adults as applied to children is not achievable without significant service investment in workforce and training in existing mental health and eating disorder services. The waiting time standard can only be applied to children and young people and not generalised to cover all people or adults.
- Support for using the same timeframe for adults to ensure equality with services for all ages. However, a query was raised on the evidence of using adults for this timeframe. Stating expert opinion would address this.
- Both the assessment timeframes of within 24 hours for high risk cases and the urgent cases of treating within a week is not required in adult eating disorder services as they will need community mental health teams or crisis team input. Existing assessment and waiting times need to be the focus not extra resources in rapid assessment.

5.2 Draft statement 5

People with an eating disorder who are being supported by more than one service have a care plan that explains how the services will work together.

Consultation comments

Stakeholders made the following comments in relation to draft statement 5:

- General support for statements 5 and 6 on coordinated care which are related but distinctly different.
- The GP and care coordinator roles are vital for care planning and therefore should be made more explicit.
- It's important to state that the care plan must be personalised in the process measure.
- Query on outcome measures on relapse rates and engagement with services in terms of their relevance to the person being supported with a care plan.

5.3 Draft statement 6

People with an eating disorder who are moving between services have their risks assessed.

Consultation comments

Stakeholders made the following comments in relation to draft statement 6:

- General support for statements 5 and 6 on coordinated care which are related but distinctly different.
- Monitoring is needed throughout the transition period between services rather than just a risk assessment at a single point in time. Suggestion to add the term 'risk management' to capture both risk assessment and monitoring.
- For people moving between geographical areas (including students) the transition protocols referred to should include home-based services (such as their GP and/or current eating disorders service) contacting the service(s) in the person's term-time area to arrange for an appointment to take place soon after arrival.
- Include Royal College of Psychiatrists' publication CR208 'Managing transitions when the patient has an eating disorder: Guidance for good practice' as supporting info.
- More formal transition arrangements were supported. A query was raised on how the care plan will be communicated as difficulties were reported in arranging face to face meetings with all parties in attendance. Also, not all patients may require a face to face meeting. A minimum telephone contact between services in advance of transitions was suggested.

- Service disputes need to be stated and addressed. Suggestion to include a recommendation in the Parliamentary and Health Service Ombudsman (PHSO) 2017 report Ignoring the alarms: How NHS eating disorders services are failing patients on cross organisational boundaries. This highlights the need for improving shared care working protocols.
- The outcome measure of service user experience of eating disorder services is vague.

6 Suggestions for additional statements

The following is a summary of stakeholder suggestions for additional statements.

- Self-referral to eating disorder services
- Not using single measures such as BMI to determine access.
- Access and outcome measures for Anorexia Nervosa.

Appendix 1: Quality standard consultation comments table – registered stakeholders

ID	Stakeholder	Statement number	Comments[1]
1	BEAT	General	Beat is the UK's eating disorder charity. We exist to end the pain and suffering caused by eating disorders. We are a champion for those who suffer from the dreadful physical and psychological effects of these terrible illnesses. At the first phase of consultation, 26 Beat volunteers with lived experience of eating disorders contributed towards our response. All these volunteers were invited to assist us again and 13 were able to do so this time. These volunteers were asked to read both the latest draft Quality standard and the Equality Impact Assessment before sending us their answers to the consultation questions. Their feedback has influenced what we have said in this response and we have included quotes from volunteers, along with their first-name (following their permission). We are pleased to see that the Quality Standard Advisory Committee (QSAC) has decided to make many of the key changes we recommended in our response to the first phase of consultation. Also, we appreciate the recognition of our response within the minutes of the QSAC post-consultation meeting. **Summary of this response** Question 1: We welcome the addition of the new quality statements, but highlight the omission of a statement covering access to services for those who have not yet received a referral. [Comments 2-14] Question 2: We highlight the importance of qualitative data, including feedback from service-users, parents or carers and health professionals. [Comments 15-16] Question 3: We express concern at the lack of resources available to many eating disorders services, the potential for the quality standard to highlight services which are in particular need of additional investment and the potential for implementation to lead to cost-savings, through increased recovery rates and reduced need for inpatient care. [Comment 17] Question 4: We argue that Quality statement 1 should be extended to include adults, so that it can help to provide greater transparency and contribute towards building the case for additional investment in adult eating disorders services. [Comment 18]

---

[1] PLEASE NOTE: Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how quality standards are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its staff or its advisory committees.

2	BEAT	General	The achievement of the new quality statements is largely dependent on sufficient funding, workforce and training being provided to eating disorders services and other relevant services. Whilst in recent years additional funding has been allocated to Clinical Commissioning Groups (CCGs) to spend on CAMHS-ED services, the Mental Health Five Year Forward View Dashboard and reports from service-leads suggest that funding has been diverted in some areas towards other priorities. Crucially in recent years no additional funding has been provided to adult eating disorders services and most adult eating disorders services are significantly underfunded. Given this context it will be crucially important that commissioners and others who use this quality standard to assess local services take care to understand the underlying causes of apparent poor performance and then take reasonable and progressive steps to address these. We hope that the application of this quality standard will help to highlight variations in the quality of care and in so doing help to build the case for additional investment. “I have never met anyone who has been through Eating Disorder Services who thinks they have enough resources. The new statements are excellent but I don't think it is possible, certainly in my area, for these to be achieved without significant investment in staffing in the Eating Disorder Service. I also believe that GPs will require extra training on the amended quality standard and associated referral pathway as this is essential to assessing who is in need of services.” (Sophie). Reducing waiting times from referral to the start of treatment and improving the coordination of care both when people receive treatment from multiple services and when they move between services, will in time lead to cost-savings through improved recovery rates and reduced subsequent use of health services, in particular reduced inpatient admissions.
3	BEAT	General	The ‘Improving Outcomes’ section includes a bullet point which states: “service user experience of primary, secondary and outpatient care”. Outpatient care is usually classed as part of secondary care and the quality standard would also be relevant to the service user experience of daypatient, home-based treatment and inpatient care.

4	British Society of Gastroenterology & Royal College of Physicians	General	Most areas will have some form of CAMHS service and therefore should be able to make some progress against the quality statements. The provision of care for adults is extremely variable and we know of patients being sent long distances and even across national borders to receive care. There is also significant reliance on contractors in the private sector. The quality statements will, therefore, not be achievable in many areas. The Quality Statement makes no reference to the private sector, nor is there an obligation for them to provide evidence, so the implementation will remain questionable. The BSG believes that the provision of services for patients with eating disorders requires a more in depth review and greater guidance nationally, before the quality improvement statements will have any impact.
5	British Society of Gastroenterology & Royal College of Physicians	General	The access times for patients are based entirely around children and young people and the provisions for services for adults only seem to be included as an afterthought. In principal the same criteria should apply should apply to adults and younger people, with patients that are at “high risk” being seen within 24 hours and those that are less urgent within 4 weeks. As indicated before, however, the definitions of “urgent” and “non-urgent”, and of “high” and “low” risk are inadequately defined, making the Quality Statement largely meaningless. In general all the quality statements would benefit from much tighter definitions than those that are presented in the document.
6	British Society of Gastroenterology & Royal College of Physicians	General	In summary therefore the BSG believes that some improvements have been made to the original quality statements, but that in their current form they remain inadequate. If services are to be improved, then NICE needs to make much firmer statements about training, the availability of specialist eating disorder units, inpatient care, the provision of seamless care between inpatient medical units and eating disorder units and the recognition that the treatment of eating disorders should constitute a recognised speciality within psychiatry.

	NHSE-CAHMS	General	1. Family Therapy is designed to address communication and relationships where these are difficult – if communication and relationships are easy, there is often less need for family therapy as an intervention – so excluding situations which might be seen to make communication and relationships difficult is actually excluding a context where family therapy can be at its most powerful and effective as a psychological therapy. 2. At the very start of foundation courses in family therapy there is always a question: "What is a family?" – the family is a system of communication and relationships that the family themselves determine membership of, and whose goals are to thrive as a such a system (an autopoietic system, if you are interested) – so families where the children are looked after definitely qualify; and families where an abusive parent/ family member is no longer welcome can still access, utilize and benefit from family therapy without (and rarely but possibly with) the involvement of the perpetrator. In practice with all families, the membership of sessions are carefully negotiated and agreed with the family members seeking input. There are also numerous approaches methods and techniques within the family therapy canon which can help families process and understand the ramifications/ impact of any abuse in the absence of the perpetrator (as well as techniques aimed at supporting perpetrators accepting responsibility for their behaviour and its impact - though usually this is held separate from the person they have abused).
7	Royal College of General Practitioners	General	Amended Quality Standards 1,5,6 sensible and helpful
8	Royal College of Paediatrics and Child Health	General	The content all seems very appropriate and the remit appears to focus on initial care stages - we do not identify any issues with the document.
9	Department of Health and Social Care	General	I wish to confirm that the Department of Health and Social Care has no substantive comments to make, regarding this consultation
10	Royal College of Nursing	General	This is to inform you that the RCN had no comments to submit to inform on the 2nd consultation on the NICE Eating Disorders Quality Standards.

11	Faculty of Dental Surgery of the Royal College of Surgeons of England	General- Ignoring the Alarms report: How NHS eating disorders services are failing patients	On Page 2 it talks of further training of the workforce and from my work on the NICE guidelines there was little understanding that Dental issues might be the first indication of a problem and that would need to be highlighted along with the importance of dental interventions to both save teeth and improve quality of life through self-esteem. Dentists need advice on how to discuss such matters with patients , in front of parents who may not be aware or how to appropriately refer even if the patient does not want that if their life is at risk.
12	Faculty of Dental Surgery of the Royal College of Surgeons of England	General- Ignoring the Alarms report: How NHS eating disorders services are failing patients	Similar comments are applicable on Page 5.
13	Faculty of Dental Surgery of the Royal College of Surgeons of England	General- Ignoring the Alarms report: How NHS eating disorders services are failing patients	Page 15 talks about training f or GMP's but we should input for GDP's too, on the same page it talks of GMC influences but we should lobby the GDC in the same way.
14	Faculty of Dental Surgery of the Royal College of Surgeons of England	General- Ignoring the Alarms report: How NHS eating disorders services are failing patients	On Page 13 it mentions funding and this might be something we might want to comment on from a dental viewpoint too.

15	Faculty of Dental Surgery of the Royal College of Surgeons of England		Simply there are 4 questions on Page 3 which the answers are Q1 Yes Q2 Unlikely – why not consider regional centres to collect and coordinate data but also improve centres of excellence for difficult case. Hu b and spoke Q3 Yes use of allied services can reduce overall costs and increase effectiveness in the long term Q4 Yes
16	Glasgow and Clyde Adult Eating Disorder Service (AEDS)	Question 1	Statements 1, 5 and 6- Yes
17	Royal College of Psychiatrists	Question 1	We welcome the additional statements, particularly statement 1: ‘People with suspected eating disorders who are referred to an eating disorder service start assessment and treatment at the earliest opportunity’. However, there needs to be parity between CAMHS and adult specialist eating disorder services, and the recommendations need to be consistent and specific across the age range. We agree that the new quality statements reflect the key areas for quality improvements, although we would like to argue that risk assessment and management should be a key priority of eating disorder services throughout the care pathway (Standards 1-6). A patient’s deterioration can go unnoticed in poorly staffed services even without transition. However, we agree that transition between services and organisations carries particularly high risk.
18	Faculty of Dental Surgery of the Royal College of Surgeons of England	Question 1	Yes
19	BEAT	Question 1	We welcome the addition of the new quality statements, but highlight the omission of a statement covering access to services for those who have not yet received a referral. [Comments 2-14]

20	British Society of Gastroenterology & Royal College of Physicians	Question 1	The British Society of Gastroenterology strongly supports the provision of specialist services for patients with eating disorders (ED) of all ages. In our opinion the key issues that affect that goal are: 1 The availability of services across England and Wales – we know that the availability is very variable and in some localities virtually absent. 2 The specialist services should be available to all age groups. – The current quality standard is primarily directed at services for children and young people and contains little that is specific to services for adults. 3 Quality of care depends on the availability of health care professionals with a specialist interest in eating disorders. In particular there are shortages of Psychiatrists with a specialist interest in ED. Psychiatric training does not recognise eating disorders as a specialist area in their own right, in contrast to CAMHS, or Liaison Psychiatry. Even estimating the number of ED specialists is difficult. Secondly eating disorder services are essentially multidisciplinary teams and must have adequate numbers of Dieticians, Clinical Psychologists and Psychiatric Nurses experienced in the area. There is a national shortage of all of these key professionals. The quality standard makes no reference to training or to ensuring that adequate numbers of professionals are available. This is a fundamental flaw which has not been addressed in the revision. 4 The quality standard is extremely vague about what is meant by “services”. It is accepted that ED affect a wide age range from people in their early teen’s right through to an increasing number of adults in later life. The standard concentrates predominantly on younger people without recognising the needs of older woman and men. Although this is recognised as an issue in the equality impact assessment, the quality standard itself contains no description as to how this should be addressed. 5 The most severely ill patients with eating disorders are those with anorexia nervosa. The quality standard makes specific reference to patients with binge eating disorder, which actually has a low mortality and to bulimia nervosa, but makes no specific reference to improving the care of patients with anorexia nervosa which is by far the most dangerous of the conditions. It is also well recognised that patients with anorexia nervosa need access to a wider range of services. The most severely ill may require inpatient psychiatric care, preferably in a Specialist Eating Disorder Unit, but their safety is greatly increased if they also have access to Medical Specialists with an interest in Nutrition and in particular experience in refeeding severely malnourished patients.

			6 Patients who have been inpatients do better if they have access to step down care, such as day care programmes after discharge, but this is not mentioned in the quality standard. 7 Finally adequate provision of outpatient services, to allow early diagnosis and treatment may help to prevent admission for specialist care, and so may have cost savings implications. Again the quality standard completely fails to make any meaningful comment about the availability of services, close to where the patient lives, in all geographical areas.. 8 For these reasons we believe that the inclusion of the new statement does not accurately reflect the key areas for quality improvement and has failed to move the document on from its earlier draft.
21	Faculty of Dental Surgery of the Royal College of Surgeons of England	Question 1- statements 1,5 and 6	Yes
22	Oxford Health NHS Foundation Trust	Question 1-statement 1	Similar to children and young people, adults with eating disorders need timely assessment and treatment and this is a key area for quality improvement. We therefore welcome these new statements as suggested by the quality standard advisory committee.
23	Oxford Health NHS Foundation Trust	Question 1-statement 5	Yes, it reflects the key areas for quality improvement.
24	Oxford Health NHS Foundation Trust	Question 1-statement 6	Yes, it includes key areas for quality improvement.
25	BEAT	Question 2- All statements	It is important that qualitative data from service-users, their parents and carers (if appropriate) and health professionals is collected to help monitor the implementation of the quality statements. Qualitative data can supplement quantitative measures to provide detail on personal experiences of care.
26	Royal College of Psychiatrists	Question 2	Local systems and structures are in place to collect data for the proposed quality measures.

27	British Society of Gastroenterology & Royal College of Physicians	Question 2	The BSG again emphasises variable availability of specialist ED services within England and Wales. Many areas do not have specialists with an interest in Eating Disorders or specialist units dedicated to eating disorders. It is very unlikely that local systems and structures will be in place across all areas in England and Wales.. A more fundamental problem for data collection is that some of the terms used in the standard are defined very poorly. For example in quality statement 1: The denominator described as "the number of children and young people with suspected eating disorders who are classified as 'high risk' by an eating disorder service," but the definition of 'high risk' is not stated. If the denominator is inadequately defined, then the data will be largely meaningless, irrespective of how it is collected. Similarly in subsection B, the only data referred to relate to children and young people and again there is no classification as to what counts as an urgent case. The data are therefore unlikely to be reliable, or reproducible between different geographical areas, The ability to put data collection services in place will depend on the availability of specialist services and unless a more comprehensive plan is developed for England and Wales it will not be achievable.
28	Faculty of Dental Surgery of the Royal College of Surgeons of England	Question 2	Unlikely – why not consider regional centres to collect and coordinate data but also improve centres of excellence for difficult case. Hu b and spoke
29	Oxford Health NHS Foundation Trust	Question 2-statement 1	Data collection is feasible and generally well established. However, the mental health data set needs clarification and amendment to reflect the complexity of treatment provided in CAMHS ED service and the NICE Guidelines (2017). The numerators and denominators should apply to all ages and not just children and young people.

30	Glasgow and Clyde Adult Eating Disorder Service (AEDS)	Question 2- statement 5	Somewhat. At present it would be possible to audit care plans on GG&Cs electronic record keeping system. However not all services use this system (e.g. physical health versus mental health; outpatient versus inpatient). There is also no real way to know if a care plan uploaded by an individual has been agreed by all services involved. In addition there are a range of different types of care planning documentation used across the country and indeed the NHS as a whole. Lack of centralised documentation may also create problems in data collection. CPA would provide a way to achieve this more uniformly. Electronic record keeping systems can be used to identify contacts between staff members including meetings as an additional way of assessing this measure.
31	Oxford Health NHS Foundation Trust	Question 2-statement 5	Data collection is feasible. Data collection within inpatient services (especially in CAMHS ED) needs further development.
32	Glasgow and Clyde Adult Eating Disorder Service (AEDS)	Question 2-statement 6	As per our response to the previous statement it would be possible to identify risk screens have been completed via electronic record keeping systems. However the mere presence of a risk screen, does not indicate the quality of the document, or if this has been compiled in a multidisciplinary, multiagency fashion. Please see the points listed below.
33	Oxford Health NHS Foundation Trust	Question 2-statement 6	Data collection is feasible.

34	Royal College of Psychiatrists	Question 3	There are major resource implications for services and commissioners to meet these standards, particularly standard 1 and standard 2. Adult eating disorders have been underfunded and under resourced for decades, and it is therefore highly unlikely that the standards will be met by current adult eating disorders services. However, it is essential that the NICE quality standards should be based on the evidence-base and ensure parity with services for children and young people. A firm recommendation by the NICE quality standards advisory committee for parity in waiting times will help ensure that investment will follow in years to come. The Access and waiting time standard for children and young people with eating disorders: the commissioning guide (AWTS, NHS England, 2015) links staffing levels to the number of referrals or population sizes and a similar approach should be followed for adults. Still, very few CAMHS eating disorder services are yet funded to this requirement. Early treatment has the potential of cost saving owing to a reduction in the number of hospital admissions.

35	BEAT	Question 3- All statements	The achievement of the new quality statements is largely dependent on sufficient funding, workforce and training being provided to eating disorders services and other relevant services. Whilst in recent years additional funding has been allocated to Clinical Commissioning Groups (CCGs) to spend on CAMHS-ED services, the Mental Health Five Year Forward View Dashboard and reports from service-leads suggest that funding has been diverted in some areas towards other priorities. Crucially in recent years no additional funding has been provided to adult eating disorders services and most adult eating disorders services are significantly underfunded. Given this context it will be crucially important that commissioners and others who use this quality standard to assess local services take care to understand the underlying causes of apparent poor performance and then take reasonable and progressive steps to address these. We hope that the application of this quality standard will help to highlight variations in the quality of care and in so doing help to build the case for additional investment. “I have never met anyone who has been through Eating Disorder Services who thinks they have enough resources. The new statements are excellent but I don't think it is possible, certainly in my area, for these to be achieved without significant investment in staffing in the Eating Disorder Service. I also believe that GPs will require extra training on the amended quality standard and associated referral pathway as this is essential to assessing who is in need of services.” (Sophie). Reducing waiting times from referral to the start of treatment and improving the coordination of care both when people receive treatment from multiple services and when they move between services, will in time lead to cost-savings through improved recovery rates and reduced subsequent use of health services, in particular reduced inpatient admissions.

36	British Society of Gastroenterology& Royal College of Physicians	Question 3	Most areas will have some form of CAMHS service and therefore should be able to make some progress against the quality statements. The provision of care for adults is extremely variable and we know of patients being sent long distances and even across national borders to receive care. There is also significant reliance on contractors in the private sector. The quality statements will, therefore, not be achievable in many areas. The Quality Statement makes no reference to the private sector, nor is there an obligation for them to provide evidence, so the implementation will remain questionable. The BSG believes that the provision of services for patients with eating disorders requires a more in depth review and greater guidance nationally, before the quality improvement statements will have any impact.
37	Faculty of Dental Surgery of the Royal College of Surgeons of England	Question 3	Yes use of allied services can reduce overall costs and increase effectiveness in the long term

38	Glasgow and Clyde Adult Eating Disorder Service (AEDS)	Question 3-statement 1	We did not think this standard would be achievable at present. There are a number of factors which act as barriers. i) Urgency of assessment is determined based upon referral information. Referral information is often inadequate – lacking key information, such as an up to date weight, which may cause a delay in access to services. ii) Whilst urgent assessments may be undertaken quickly, CMHTs have limited numbers of staff who are adequately trained in the provision of psychological therapies for Eating Disorder. This too may cause a delay in treatment commencing. iii) Lack of clarity/ conflicting information about where responsibilities lie may also create a delay in important aspects of treatment. For example NICE suggests GPs should undertake physical health monitoring and recent changes to GP contracts undermine this. iv) CMHTs are under resourced and over pressured, this lack of resource/ capacity will also impact on speed of delivery of treatment. v) The Glasgow Adult Eating Disorder Service is set up as a tertiary service and without significant investment would not be able to be involved in every eating disorder case. This is of relevance as all ED cases are therefore initially seen within the CMHT. Investment in training of CMHT staff, and improved skill mix within CMHTs would increase accessibility of psychological therapies and therefore hopefully decrease waiting times. Whilst this may require an initial investment, prognosis of patients may improve with earlier intervention and lead to decreases in relapse and hospital admissions providing cost savings.

39	Oxford Health NHS Foundation Trust	Question 3-statement 1	Adult eating disorders have been underfunded and under resourced for decades, and it is therefore highly unlikely that the standards will be met by current adult eating disorders services. However, it is essential that the NICE quality standards should be based on the evidence-base and ensure parity for adult services with services for children and young people. A firm recommendation by the NICE quality standards advisory committee for parity in waiting times will help ensure that investment will follow in years to come. The Access and waiting time standard for children and young people with an eating disorders: commissioning guide (AWTS, NHS England, 2015) links staffing levels to the number of referrals or population sizes and a similar approach should be followed for adults. When the workforce calculator in AWTS is applied to adult services it also highlights how poorly adult services are resourced. The standard is not fully achievable in child/adolescent services without funding as recommended in the AWTS. Very few CAMHS eating disorder services are yet funded to this requirement. Adequate resourcing for early intervention would save money in the long term due to prompt treatment before the eating disorder gets established and is harder to treat. The BEAT/PWC, 2015 report stated: ‘Based on prevalence estimates drawn from previous studies, of between 600,000 and 725,000, these costs suggest – assuming a ratio of 1 carer to 1 sufferer – an annual direct financial burden of between £2.6 billion and £3.1 billion on sufferers and carers, total treatment costs to the NHS of between £3.9 billion and £ 4.6 billion (and, potentially, a further £0.9 – £1.1 billion of private treatment costs) and lost income to the economy of between £6.8 billion and £8 billion’. Consequently, an investment in adult services (which have significant larger caseloads) of 2-3 times the £150 million that was invested in CAMHS eating disorders services, will bring about significant financial savings to sufferers, carers, the NHS and economy. The costs of inpatient admissions are about £40-50 K per patient and investments in adult community services and early assessment and treatment is likely to reduce the inpatient spent and therefore overall costs to the NHS.

40	Glasgow and Clyde Adult Eating Disorder Service (AEDS)	Question 3- statement 5	In theory yes. However as noted in our answer above there are a number of practical issues which may be barriers to real world implementation of this standard: i) Different processes across services and localities. ii) Service pressures make it difficult to get clinicians together to fully discuss care plans iii) Difficulties in determining where final responsibility lies for completion of documentation where a number of services are involved iv) There may be differences in opinion between services about responsibilities and political factors such as funding may impact upon this. Investment in services would improve these factors and would allow for the provision of higher quality co-ordinated care, which would likely result in lower costs longer term.
41	Glasgow and Clyde Adult Eating Disorder Service (AEDS)	Question 3-statement 6	We would argue that all ED patients should have a risk assessment, not only at the point of transition. We would agree that times of transition are associated with increased risk both of relapse and of suicide and that risk assessment is therefore of vital importance at these times. Whist we would hope that services do undertake risk assessments, our argument would that these are often not agreed between services in advance of transitions, with associated planning therefore lacking. The team felt that more formal transition arrangements would improve this process which should include ideally face to face contact or at a minimum telephone contact between services in advance of transitions. A key barrier is service pressures and lack of resourcing. It is again difficult to arrange face to face meetings with all stake holders in attendance. However the quality of risk assessment may suffer as a consequence. Short term time invested in this process may improve patient outcomes and divert from relapse, hospital admissions and critical incidents, so longer term this represents a valuable investment by services.
42	Oxford Health NHS Foundation Trust	Question 3-statement 6	There are resource implications for safe risk management in the transition between CAMHS and adult services, as waiting times for starting treatment within adult services are unacceptably long.

43	Faculty of Dental Surgery of the Royal College of Surgeons of England	Question 4	Yes

44	BEAT	Question 4-statement 1	In our response to the first phase of the consultation we emphasised the importance of reducing waiting times for adults as well as children and young people. The capacity for the same referral to assessment and treatment times specified in the 'Access and waiting time standard for children and young people with an eating disorder commissioning guide' to be widely achieved for adults, would depend on sufficient funding, workforce and training being provided to adult eating disorders services. "*I certainly think that these referral and treatment times would be achievable for adults, however in my experience I am not sure that this is possible with the current resources in my local area*…" (Sophie). However, if Quality statement 1 was broadened to include adults, and it was applied fairly (see our answer to Question 3) it could be a useful tool to raise awareness about the scale of the challenge and geographic variation (particularly since such statistics are not published nationally by NHS Digital or NHS England). It could help to build the case for additional investment in adult eating disorders services. Although there are no national quality indicators on this issue, NICE's 'Quality Standards Process guide' explains that this need not necessarily prevent inclusion. The data published by the Care Quality Commission in Figure 3 of their 'The State of Care in Mental Health Services: 2014-2017' report suggests that there are at least some providers with the capacity to measure and report waiting times at their adult eating disorders services. Whilst we recognise that the QSAC must consider whether quality statements might be 'achievable', we also note that on some occasions NICE includes quality statements which describe "*developmental practice*", indicating "*outstanding performance*". If applied without fair consideration to the lack of resources available to many adult eating disorders services, then this increased scrutiny on waiting times could damage staff morale and potentially lead to elevated 'thresholds' for access to services in some areas. It could also lead to other steps which would damage patient care, such as arbitrary limits being applied to the duration of treatment or the over-zealous discharge of patients following non-attendance.

45	British Society of Gastroenterology& Royal College of Physicians	Question 4-statement 1	The access times for patients are based entirely around children and young people and the provisions for services for adults only seem to be included as an afterthought. In principal the same criteria should apply should apply to adults and younger people, with patients that are at “high risk” being seen within 24 hours and those that are less urgent within 4 weeks. As indicated before, however, the definitions of “urgent” and “non-urgent”, and of “high” and “low” risk are inadequately defined, making the Quality Statement largely meaningless. In general all the quality statements would benefit from much tighter definitions than those that are presented in the document.
46	Glasgow and Clyde Adult Eating Disorder Service (AEDS)	Question 4-statement 1	Given the factors mentioned in our answer to Q3, we did not feel it was possible, without substantial service investment in psychological therapies training and supervision, for adult services to achieve the same waiting time to treatment standard as is applied to CAMHS.
47	Oxford Health NHS Foundation Trust	1	Adult eating disorder service have been underfunded for decades despite increasing referral rates, etc. Consequently, current adult services will not be able to meet these assessment and treatment times that were set for children and young people services. However, one could also argue that the absence of waiting time targets for adults have maintained the problem as standards tend to improve services and highlight funding needs.

48	Autistica	1	To achieve its stated aim of improving recovering rates, this quality standard needs to alert commissioners, providers and practitioners that many people with eating disorders, particularly anorexia nervosa, will be autistic. When people with suspected eating disorders are assessed and social difficulties are prominent, consideration needs to be made for whether the person has a neurodevelopmental condition, such as autism. Autism is not usually recognised or identified as a factor in these assessment but it will impact on the nature of that person's eating disorder, their ability to access services and potentially the treatment they need. A significant proportion of people with anorexia nervosa are autistic Studies consistently show that between 20 and 30% of women with anorexia nervosa are autistic. Furthermore there is strong evidence that these figures represent the presence of 'true autism' and not a phenocopy resulting from anxiety or starvation. , The autistic characteristics of women with AN have been found to predate their eating disorder , and the prevalence of autism remains high in samples of women who have restored body weight after recovering from anorexia nervosa. Under existing practice autistic people with eating disorders experience particularly poor outcomes The lack of recognition of autistic people within this quality standard is deeply concerning, as there is evidence that eating disorder services are currently failing to meet autistic people's needs. Amongst patients with anorexia nervosa, autistic people have been found to benefit the least from existing interventions and care pathways , and have the worst outcomes, with particularly low rates of recovery and levels of functioning. A growing body of evidence is demonstrating the importance of adapting mental health interventions and pathways to better suit autistic people. , , , , As it stands, clinicians following this quality standard (and other NICE guidance on eating disorders) will have no indication that they may need to make adaptations for a significant and distinct proportion of their patients.

49	BEAT	1	We are pleased to see that the QSAC has responded to the feedback from Beat and other stakeholders, which called for the quality standard to address the topic of access to services. We welcome that statement 1 covers the extremely important issue of waiting times from referral to assessment and treatment. “Statement 1 is extremely important if we are to move forward to improve care for people who suffer from anorexia. My daughter's illness became extremely serious because there were so many delays in diagnosing and starting treatment for her illness. Initially it was thought that she could be treated as an outpatient but it soon became clear that she needed inpatient care and she was in an Eating Disorder Unit for 8 months. We saw this pattern repeated again and again as new patients were admitted to the unit. It would have been a much less traumatic experience for [my daughter] and also for the rest of our family if she could have been treated as an outpatient. This can also only have a beneficial effect on the already stretched resources of the NHS.” (Margaret).
50	BEAT	1	The QSAC should consider amending the wording of Quality statement 1 (QS1) to provide greater clarity that it is relevant to a) patients who refer themselves (self-refer) and b) adults who are referred to a mental health service other than an eating disorders service. a) The current wording of “people with suspected eating disorders who are referred to…” (emphasis added) may imply an expectation for clinical ‘gatekeeping’ to referrals. It is important that people who self-refer are not excluded from this quality statement. b) Some areas do not have a local adult eating disorders service, and so adults are referred to a non-specialised adult mental health service. This point will still be relevant if the QSAC decides against extending QS1 to include adults, as 18-year-olds are covered by the ‘Access and waiting time standard for children and young people with an eating disorder’.
51	BEAT	1	The ‘Access and Waiting Time Standard for Children and Young People with an Eating Disorder’ specifies that the 1 week/4 week timescales apply to the period between the date of referral (including self-referral) and the start of treatment. The quality measures proposed are not clearly worded in this respect and so there is a risk that they could be misunderstood. The use of “within X weeks of first contact with a designated health professional” (emphasis added) could be misunderstood to mean that the waiting times ‘clock’ should start at assessment rather than at referral.

52	BEAT	1	Whilst statement 1 is an important addition, it should be noted that this statement appears to only cover ‘access to services’ for those who have received a referral for eating disorder treatment. As highlighted in our response to the first phase of consultation and subsequently by many of the volunteers who assisted us with this response, there are often significant barriers encountered by people with eating disorders which prevent or seriously delay them receiving a referral. “The majority of my peers who are in Recovery, had a very short duration of illness and prompt treatment. I experienced years of missed opportunities by medical professionals between the onset of my Anorexia Nervosa and diagnosis. Though I was fortunate enough to receive immediate treatment once assessed by an eating disorder specialist, by then my false beliefs, unhealthy behaviours and rigid anorexic rules were deeply entrenched. I have since spent almost twenty years battling to overcome this horrific illness.” (Lara) We appreciate that new quality standards typically contain only 5 statements, but if the QSAC is at liberty to consider the inclusion of a seventh draft statement in this quality standard, then we recommend that it considers the inclusion of a statement based around either self-referral (see NICE NG69 Rec. 1.1.2) or the use of single measures, such as a maximum BMI, to determine access to treatment (see NICE NG69 Rec. 1.2.8). “Our GP recognised that there was a problem with our daughter's mental health when her BMI was still quite normal. [My daughter] told her that she was restricting her food and that she was extremely anxious. The psychiatric service that she was referred to said that her BMI was nowhere near low enough for her to be considered for treatment and she was passed back to the GP for counselling. This situation of being passed from one department to another continued until [she] became extremely ill and was taken in to hospital as an emergency…” (Margaret) “…I think that self-referral would be an excellent idea. Many people feel embarrassed or ashamed about their Eating Disorder and being able to self-refer would make access to a specialist service more immediate and less anxiety-inducing.” (Sophie) If a statement was to be inserted on self-referral, it should emphasise that choosing to self-refer should not prevent or delay the person from accessing a specialist assessment (relative to those referred from a GP or other established referral route).

			Please note that we would not support the inclusion of this new statement if it were to come at the expense of Quality statements 5 and 6 being amalgamated (see comment number 8) or one of these two quality statements being dropped.
53	BEAT	1	Another aspect of ‘access to services’ which is a key area for quality improvement in many areas, is the rejection of referrals. Of course, in some cases there will be clinically valid reasons for referrals to be redirected to another service, however in many cases referrals are rejected due to services not having sufficient capacity or the use of single measures such as BMI to determine whether to offer treatment (in contravention of NICE NG69 Rec 1.2.8). It is not clear whether the denominators in measures b) and c) will include those people who are referred and assessed but who are not offered treatment.

54	British Society of Gastroenterology & Royal College of Physicians	1	The term “earliest opportunity” needs to be more closely defined and should state 4 weeks. This is recommendation has already been made to commissioners for children’s services.. It should be made clear that this also applies to adults. The problems around the definition of urgency, severity and risk has already been made. The measured outcome that is stated as “the recovery rate of people with eating disorders” is extremely vague. Firstly the recovery rate varies between the different diagnoses, with better outcomes in binge eating disorder and bulimia nervosa, than in anorexia nervosa, which is recognised as a more difficult condition to treat. As a minimum, therefore, the recovery rate in each of the conditions should be measured, rather than globally for eating disorders in general. In anorexia nervosa,varying degrees of recovery are to be expected. About 1 in 3 patients are thought to recover completely whilst a further 1 in 3 have an incomplete recovery or a relapsing course. 1 in 3 patients with anorexia nervosa probably go on to chronic illness and significant disability. What outcome measure for anorexia nervosa is being referred to in the quality standard? It is also accepted that patients with anorexia nervosa may take up to 7 years to recover. Over what period of time would the recovery rate be measured? A much closer definition is required if the statistics are to have any meaning. The paragraph ‘ definitions and terms used in this quality statement’ on page 6, defines a whole series of symptoms which are recognised in a variety of eating disorders but makes no attempt to separate what are accepted symptoms of the condition from those that indicate a degree of urgency or severity. In general, for anorexia nervosa, evidence of a low BMI, circulatory disturbance, hypothermia or low blood glucose are accepted as signs of severity and in some cases can indicate a life threatening presentation. The BSG believes that it is not acceptable to simply list the symptoms, but that there must be a better scoring system, or description, of what constitutes severity and risk

55	Faculty of Dental Surgery of the Royal College of Surgeons of England	1	Quality statement should be more precise about MDT construct like cancer and should include Dentistry. At least Page 7 does include Dental but on page 8 the question for consult should include Dental.
56	Glasgow and Clyde Adult Eating Disorder Service (AEDS)	1	At present there is varying consistency in how diagnostic information is recorded on Glasgow's electronic notes system (EMIS). Data may therefore be inaccurate (likely to under estimate number of ED cases as per recent audit by AEDS). Further locality guidance on recording (and who has responsibility for entering diagnostic data) could improve this. Diagnostic information alone would not highlight if ED was long standing/ first presentation etc… and therefore may not accurately indicate where early intervention has taken place. This information would need to be accessed via letters/ clinical notes and this would be time consuming. Recovery rates and relapse rates are likely to be difficult to measure. Local electronic record keeping systems do not at present hold templates of outcome measures. Patients may represent with a different primary difficulty.

57	Glasgow and Clyde Adult Eating Disorder Service (AEDS)	1	We did not think this standard would be achievable at present. There are a number of factors which act as barriers. i) Urgency of assessment is determined based upon referral information. Referral information is often inadequate – lacking key information, such as an up to date weight, which may cause a delay in access to services. ii) Whilst urgent assessments may be undertaken quickly, CMHTs have limited numbers of staff who are adequately trained in the provision of psychological therapies for Eating Disorder. This too may cause a delay in treatment commencing. iii) Lack of clarity/ conflicting information about where responsibilities lie may also create a delay in important aspects of treatment. For example NICE suggests GPs should undertake physical health monitoring and recent changes to GP contracts undermine this. iv) CMHTs are under resourced and over pressured, this lack of resource/ capacity will also impact on speed of delivery of treatment. v) The Glasgow Adult Eating Disorder Service is set up as a tertiary service and without significant investment would not be able to be involved in every eating disorder case. This is of relevance as all ED cases are therefore initially seen within the CMHT. Investment in training of CMHT staff, and improved skill mix within CMHTs would increase accessibility of psychological therapies and therefore hopefully decrease waiting times. Whilst this may require an initial investment, prognosis of patients may improve with earlier intervention and lead to decreases in relapse and hospital admissions providing cost savings.
58	Leicestershire Adult Eating Disorders Service	1	We agree with this statement in the principle. However, we do not think that Adult services will be able to offer assessment and treatment in the timeframe that is stated in the Access and waiting time standard, UNLESS there is a large amount of extra resource put into the existing services.

59	Leicestershire Adult Eating Disorders Service	1	We feel that the proposed timescales (for urgent cases assess within 24 hours and treat within 1 week) are not required in an adult eating disorder service. We feel that if some one requires assessment within 24 hours, the urgency is unlikely to be about their need for a psychological therapy for their eating disorder. Urgent adult ED patients may be ‘urgent’ due to physical problems e.g low weight. these patients need to go to the ED/ Medical ward. They will not benefit from being seen by a therapist in an ED service. The other group of patients who could be seen as urgent are those who are acutely suicidal. Again, the ED service is not the right place for them; they require CMHT or crisis team input. Instead of using resources to fund this rapid assessment, we would prefer to see funding going into shoring up our existing assessment and treatment waiting times.
60	Leicestershire Adult Eating Disorders Service	1	We are confused about who defines a case as ‘urgent’. Someone who works in ED is best placed to do this, but if a GP referral comes to us marked URGENT, would we be expected to keep to these timescales. We think the definition of what is urgent or routine should be done by the ED service.
61	Leicestershire Adult Eating Disorders Service	1	In this service, we do have the ability to measure how many of our patients are seen within a given timeframe.
62	NHSE-Eating disorders Advisory Group	1	This is a laudable goal but many eating disorders services are poorly resourced and consequently have long waiting lists for both assessment and treatment. This will not change unless there is substantial new investment by CCGs. There has been significant, central, ring –fenced new funding for children and young people (CYP) with eating disorders, which has reduced waiting times dramatically but there has been no equivalent funding made available for patients over the age of 18. The standard refers to “People with suspected eating disorders” (age unspecified), the specified outcomes are for “people with eating disorders” and the standard is addressed to adult services but the measures will only capture data for CYP. The term “at the earliest opportunity” is vague and unquantifiable. Consequently, this standard will give no new information about services for adults and have no effect in improving services for this neglected group. The diversity standard that there should be “equal access to services and treatment…regardless of age” is inconsistent with the current reality and with commissioning arrangements which discriminate against older patients.

63	NHSE- Clinical Policy and Mental Health Strategy Delivery and Information	1	For CYP, inpatient care is not necessarily going to be delivered by eating disorder units/services. In the pathway guidance we carefully worded this so that the focus is on the individual and not on the services available. Could the statement be rephrased to read: ‘People who are referred with suspected eating disorders start assessment and treatment at the earliest opportunity’
64	NHSE- Clinical Policy and Mental Health Strategy Delivery and Information	1	See recommended rephrasing noted on page 4 of amended pdf. Note that the eating disorder waiting time standard is deliberately set to monitor time between referral to start of treatment. While the guidance includes a recommended time frame from referral to assessment, this is not set as a set standard that is monitored. Learning from other programmes showed that do so can encourage internal waiting times.
65	NHSE- Clinical Policy and Mental Health Strategy Delivery and Information	1	Add by Data Source here and other sections below 'Local data collection, Mental Health Services Data Set (MHSDS) reports from NHS Digital (add link) and local audit of patient records.
66	NHSE- Clinical Policy and Mental Health Strategy Delivery and Information	1	The more comprehensive list used below under psychological treatments should be consistently applied under each statement so it reads '(such as community eating disorder teams, primary care, secondary care, tertiary care and non-NHS units)'
67	NHSE- Clinical Policy and Mental Health Strategy Delivery and Information	1	Re Edit - for the reason explained in the first comment above we suggest removing the phase referred ~~‘to an eating disorder service’~~

68	NHSE- Clinical Policy and Mental Health Strategy Delivery and Information	1	Re point one above – could it be rephrased to state: 'People referred with a suspected eating disorder have an assessment of their symptoms and risk factors and start of treatment as soon as possible'
69	NHSE-Primary Care Team	1	In my opinion the inclusion of the new statements accurately reflect the key areas for quality improvement; In response to the question if from referral to assessment would the treatment times also be achievable for adults as for children, primary care would welcome the treatment times to be replicated for adults based on risk classification of high risk, urgent and non-urgent, but this would be dependent on the availability of resources with the Mental Health Provider/Eating Disorder service.
70	Oxford Health NHS Foundation Trust	1	Similar to children and young people, adults with eating disorders need timely assessment and treatment and this is a key area for quality improvement. We therefore welcome these new statements as suggested by the quality standard advisory committee.
71	Oxford Health NHS Foundation Trust	1	Data collection is feasible and generally well established. However, the mental health data set needs clarification and amendment to reflect the complexity of treatment provided in CAMHS ED service and the NICE Guidelines (2017). The numerators and denominators should apply to all ages and not just children and young people.

72	Oxford Health NHS Foundation Trust	1	Adult eating disorders have been underfunded and under resourced for decades, and it is therefore highly unlikely that the standards will be met by current adult eating disorders services. However, it is essential that the NICE quality standards should be based on the evidence-base and ensure parity for adult services with services for children and young people. A firm recommendation by the NICE quality standards advisory committee for parity in waiting times will help ensure that investment will follow in years to come. The Access and waiting time standard for children and young people with an eating disorders: commissioning guide (AWTS, NHS England, 2015) links staffing levels to the number of referrals or population sizes and a similar approach should be followed for adults. When the workforce calculator in AWTS is applied to adult services it also highlights how poorly adult services are resourced. The standard is not fully achievable in child/adolescent services without funding as recommended in the AWTS. Very few CAMHS eating disorder services are yet funded to this requirement. Adequate resourcing for early intervention would save money in the long term due to prompt treatment before the eating disorder gets established and is harder to treat. The BEAT/PWC, 2015 report stated: ‘Based on prevalence estimates drawn from previous studies, of between 600,000 and 725,000, these costs suggest – assuming a ratio of 1 carer to 1 sufferer – an annual direct financial burden of between £2.6 billion and £3.1 billion on sufferers and carers, total treatment costs to the NHS of between £3.9 billion and £ 4.6 billion (and, potentially, a further £0.9 – £1.1 billion of private treatment costs) and lost income to the economy of between £6.8 billion and £8 billion’. Consequently, an investment in adult services (which have significant larger caseloads) of 2-3 times the £150 million that was invested in CAMHS eating disorders services, will bring about significant financial savings to sufferers, carers, the NHS and economy. The costs of inpatient admissions are about £40-50 K per patient and investments in adult community services and early assessment and treatment is likely to reduce the inpatient spent and therefore overall costs to the NHS.

73	Oxford Health NHS Foundation Trust	1	The assessment and treatment times are not currently achievable in adult services, given the lack of historic investment. However, this does not mean that the quality standards for adults need to be 'lower' than for young people and children. More investment and shorter waiting times for adults will only follow in the years to come once clear waiting time targets are identified and set for adult eating disorders services. A lack of clarity about acceptable waiting times for adults, will only maintain the status quo and we hope that the advisory committee will use this unique opportunity to bring clarity on the matter. The report of the parliamentary and health service ombudsman: Ignoring the alarms: How NHS eating disorder services are failing patients recommended that: The Department of Health and NHS England should review the existing quality and availability of adult eating disorder services to achieve parity with child and adolescent services. and … for good quality transitions to be the norm, there needs to be dual focus on the quality and availability of adult eating disorder services, particularly given how frequently these conditions continue into adulthood. There also needs to be greater availability of good quality adult eating disorder services, which are currently subject to significant geographical variation meaning access to specialist support can be hugely divergent. Without these changes, adult eating disorder services will remain a Cinderella service and the experiences of the people in this report will be replicated, with similarly tragic consequences. We feel that the NICE quality standards advisory committee have a unique opportunity to clarify what the waiting times for adults with eating disorders should be. This clarity will add further pressure on the Department of Health, NHS England, commissioners and service providers to ensure the quality and availability of adult eating disorders services achieve parity with child and adolescent services.
74	Oxford Health NHS Foundation Trust	1	People with suspected eating disorders who are referred to an eating disorder service start assessment and treatment at the earliest opportunity. We feel that the wording 'at the earliest opportunity' is unhelpfully vague. For example, suppose due to a lack of resources and underfunding the waiting list in the community is two years for NICE recommended treatment for adults with eating disorders, then the commissioners and service managers would still be able to say that they are compliant with the standard (i.e. given their limited resources they deliver treatment at the earliest opportunity which is after a wait of two years).

75	Oxford Health NHS Foundation Trust	1	Undiagnosed and untreated eating disorders have a significant impact on individuals, their families, the health sector and wider UK economy as highlighted by the BEAT/PWC (2015) report: The costs of eating disorders: Social, health and economic impacts. We suggest that this impact should be included in the rationale for statement 1, e.g. ‘People with eating disorders who receive early intervention in eating disorder services have better recovery rates and a reduced risk of relapse. It may also reduce the need for hospitalisation, which has additional cost benefits. Delays in starting assessment and treatment can affect the response to treatment, and the longer the delay the greater the impact on outcomes with an avoidable and prolonged burden on individuals, their families, the health sector and wider economy.
76	Oxford Health NHS Foundation Trust	1	NHS England’s Access and waiting time standard for children and young people with an eating disorder: commissioning guide (2015) includes details of referral to assessment and treatment times for children and young people with suspected eating disorders. To ensure parity between child/adolescent and adult services, we feel that it is essential that similar access and waiting times need to be introduced for adult services and that this needs to be accompanied by the required investment in adult community eating disorders services.
77	Oxford Health NHS Foundation Trust	1	a) Proportion of children and young people with suspected eating disorders who are classified as at high risk by an eating disorder service who have a face-to-face assessment within 24 hours. Based on the evidence and safe practice (rather than what is currently achievable in adult services), it will be helpful if the guidelines could stipulate what the time scale should be for assessments of adults with eating disorders who are at high risk. In order to avoid discrimination and contradict expert opinion, the quality standards advisory committee, could recommend that in years to come adult services should also endeavour to assess adults who are at high risks within 24 hours. The numerator and denominator should apply to children, young people and adults with eating disorders.
78	Oxford Health NHS Foundation Trust	1	There is no mention of Marsipan guidelines in classifying risk. As we fed back in previous comments it would be helpful to include the use of Marsipan and junior Marsipan guidelines

79	Oxford Health NHS Foundation Trust	1	b).Proportion of children and young people with suspected eating disorders and classified as an urgent case who start treatment within 1 week of first contact with a designated healthcare professional c).Proportion of children and young people with suspected eating disorders and classified as a non-urgent case who start treatment within 4 weeks of first contact with a designated healthcare professional. First contact with designated health care professional is not defined. It needs to be clear when the clock starts as this makes a difference to meeting the targets. According to the AWTS The CLOCK STARTS when the request for an eating disorder assessment is received and logged, regardless of the agency making the request.
80	Oxford Health NHS Foundation Trust	1	b) Proportion of children and young people with suspected eating disorders and classified as an urgent case who start treatment within 1 week of first contact with a designated healthcare professional. It will be helpful if the guidelines could stipulate what the time scale should be for the start of treatment for adults who are classified as urgent cases. In order to avoid discrimination and contradict expert opinion, the quality standards advisory committee, could recommend that over time adult services should also endeavour to achieve waiting times of no longer than a week for urgent adult cases. The numerator and denominator should apply to children, young people and adults with eating disorders.
81	Oxford Health NHS Foundation Trust	1	c) Proportion of children and young people with suspected eating disorders and classified as a non-urgent case who start treatment within 4 weeks of first contact with a designated healthcare professional. As mentioned above, and based on the evidence and safe practice (rather than what is achievable in adult services), it will be helpful if the guidelines could stipulate what the time scale should be for the start of treatment for adults who are classified as non-urgent cases. Unless there is a clear evidence-base against the recommendation, adult services should also endeavour to achieve waiting times of no longer than 4 weeks for non-urgent cases. The numerator and denominator should apply to children, young people and adults with eating disorders

82	Oxford Health NHS Foundation Trust	1	Service providers (such as community eating disorder teams and secondary adult mental health services) ensure that referral pathways are in place for people with suspected eating disorders to access assessment and treatment services at the earliest opportunity. Again as mentioned before, it will be helpful if the wording ‘at the earliest opportunity’ could be defined in terms of clear timescales similar to those for child and young people services (i.e. assessment of high risk patients within 24 hours; treatment within 1 week for urgent cases, treatment within 4 weeks for non-urgent cases). Alternatively, the wording could be adjusted to: Service providers (such as community eating disorder teams and secondary adult mental health services) ensure that referral pathways are in place for people with suspected eating disorders to access assessment and treatment services at the earliest opportunity. Service providers should endeavour to ensure parity in waiting times for patients of all ages.
83	Oxford Health NHS Foundation Trust	1	We suggest adding: Healthcare professionals (such as specialists within community eating disorder teams) assess people with suspected eating disorders who have been referred to an eating disorder service and start their treatment at the earliest opportunity, and endeavours to ensure parity between waiting times for patients of all ages.
84	Oxford Health NHS Foundation Trust	1	Commissioners (such as clinical commissioning groups, NHS England and local authorities) ensure that they commission services with the capacity and expertise to deliver assessment for people with suspected eating disorders and start their treatment at the earliest opportunity. We suggest adding: Commissioners ensures parity between waiting times for children, young people and adults with eating disorders.
85	Oxford Health NHS Foundation Trust	1	We suggest inserting: People, off all ages, with suspected eating disorders who are referred to an eating disorder service have an assessment of their symptoms and risk factors and start treatment as soon as possible.
86	Oxford Health NHS Foundation Trust	1	We suggest referencing the Marsipan and Junior Marsipan guidelines

87	Oxford Health NHS Foundation Trust	1	Treatment for children and young people with suspected eating disorders should start within 4 weeks of first contact with a designated healthcare professional for non-urgent cases and within 1 week for urgent cases. For high-risk cases, the eating disorder service should undertake a face-to-face assessment within 24 hours. [NHS England's Access and waiting time standard for children and young people with an eating disorder and expert opinion] If the access and waiting guidelines for children and young people are partly based on expert opinion, then it will be helpful to indicate that expert opinion suggest similar waiting times for adults with eating disorders, unless the quality standards advisory committee is aware of evidence that the waiting times for adults should be longer (or shorter) than those for children and young people.
88	Oxford Health NHS Foundation Trust	1	The draft quality standards states: In line with NICE's guideline on eating disorders, recommendation 1.1.2, equal access to services and treatment (including through self-referral) for people with an eating disorder and their parents or carers (as appropriate) is important regardless of: • age Clearly, the quality standards will be at risk of contradicting itself, the NICE guidelines and expert opinion if it differentiates between waiting times for adults versus waiting times for children/young people. In fact, one could argue that the quality standards document, in its structure and layout, should avoid having different sections for adults and young people/children unless there is a clear evidence—base for different waiting times for the age groups. The final paragraph of the draft quality standards states that neither the standards nor commissioners should discriminate unlawfully to specific groups of service users: Commissioners and providers should aim to achieve the quality standard in their local context, in light of their duties to have due regard to the need to eliminate unlawful discrimination, advance equality of opportunity and foster good relations. Nothing in this quality standard should be interpreted in a way that would be inconsistent with compliance with those duties. Finally, we wondered whether this NICE Quality Standard Document will be able to pass/fail the Equality Impact Assessment according to the NICE equality policy if it fails to recommend parity for adults with eating disorders compared to children and young people with eating disorders?

89	Royal College of General Practitioners	1	“Process Proportion of children and young people with suspected eating disorders who are classified as at high risk by an eating disorder service who have a face-to-face assessment within 24 hours.” Who defines the patient is high risk? In practice usually it is the secondary care service based on the information supplied to them. It can extremely difficult to get mental health services to assess a person with an eating disorder within 24 hours and they will often insist on an admission to hospital under either the paediatricians or the general medical team. A significant number of young people die whilst waiting for admission to an eating disorder unit. If they know they have a planned admission they often lose further weight as they know they are likely to put weight on as an inpatient.
90	Royal College of General Practitioners	1	Elimination of IBD in this group could be highlighted more clearly. Approximately 25% of patients with IBD present before age 20 years and 22% of children present with growth failure, anaemia, perianal disease, or other extraintestinal manifestations as the only predominant initial feature. Rosen, M. J., Dhawan, A., & Saeed, S. A. (2015). Inflammatory Bowel Disease in Children and Adolescents. JAMA Pediatrics, 169(11), 1053–1060. http://doi.org/10.1001/jamapediatrics.2015.1982

91	Royal College of Psychiatrists	1	‘People with suspected eating disorders who are referred to an eating disorder service start assessment and treatment at the earliest opportunity.’ This is a key area for quality improvement, which would improve patient outcomes and in the long term has the potential to reduce costs associated with eating disorders, by reducing the need for hospitalisation and long term disability. However, this statement should apply to all age groups in line with the NICE guidelines, which state that ‘all people with an eating disorder and their parents or carers have equal access to treatments (including through self-referral) for eating disorders, regardless of: age, gender or gender identity (including people who are transgender), sexual orientation, socioeconomic status,religion, belief, culture, family origin or ethnicity where they live and who they live with’. The term ‘earliest opportunity’ is too vague. Many services struggle with extensive waiting times owing to the chronic underfunding of services. This has been highlighted by research commissioned by BEAT https://www.beateatingdisorders.org.uk/uploads/documents/2017/11/delaying-for-years-denied-for-months.pdf It would also be helpful to include risk assessment in the quality statement (although this is mentioned on page 6 among definitions, it would be helpful to include it in the title).
92	Royal College of Psychiatrists	1	This only refers to children and young people, so this needs to be corrected to include all age groups. The numerator and denominator should apply to children, young people and adults with eating disorders.
93	Royal College of Psychiatrists	1	The two source guidance (page 6) include the NICE guideline and the ‘Access and waiting time standard for children and young people with an eating disorder: commissioning guide’. It is unclear in the current draft whether the latter standard should apply to adult services. Unless adult services have the same access and waiting times, this standard would not meet equality and diversity considerations.

94	Royal College of Psychiatrists	1	Whilst this is a very important quality standard, it is not possible to achieve this without sufficient staffing. ‘The Access and waiting time standard for children and young people with an eating disorder: commissioning guide’ specifies staffing levels depending on the number of referrals to the service. The same should apply to adult specialist eating disorder services. The Parliamentary ombudsman highlighted this among his recommendations: The Department of Health and NHS England (NHSE) should review the existing equality and availability of adult eating disorder services to achieve parity with child and adolescent services https://www.ombudsman.org.uk/sites/default/files/page/FINAL%20FOR%20WEB%20Anorexia%20Report.pdf NICE quality standards provide a unique opportunity to reinforce the need for parity between CAMHS and adult services.
95	Royal College of Psychiatrists	1	We suggest inserting: People, of all ages, with suspected eating disorders who are referred to an eating disorder service have an assessment of their symptoms and risk factors and start treatment as soon as possible.
96	Royal College of Psychiatrists	1	We suggest referencing Marsipan and Junior Marsipan guidelines https://www.rcpsych.ac.uk/pdf/CR189_a.pdf https://www.rcpsych.ac.uk/pdf/CR168summary.pdf
97	Royal College of Psychiatrists	1	Treatment for children and young people with suspected eating disorders should start within 4 weeks of first contact with a designated healthcare professional for non-urgent cases and within 1 week for urgent cases. For high-risk cases, the eating disorder service should undertake a face-to-face assessment within 24 hours. [NHS England’s Access and waiting time standard for children and young people with an eating disorder and expert opinion] If the access and waiting guidelines for children and young people are partly based on expert opinion, then it will be helpful to indicate that expert opinion suggests similar waiting times for adults with eating disorders. We are unaware of evidence that the waiting times for adults should be longer (or shorter) than those for children and young people.

98	Royal College of Psychiatrists	1	The draft quality standards states: In line with NICE’s guideline on eating disorders, recommendation 1.1.2, equal access to services and treatment (including through self-referral) for people with an eating disorder and their parents or carers (as appropriate) is important regardless of: • age The final paragraph of the draft quality standards states that neither the standards nor commissioners should discriminate unlawfully to specific groups of service users: Commissioners and providers should aim to achieve the quality standard in their local context, in light of their duties to have due regard to the need to eliminate unlawful discrimination, advance equality of opportunity and foster good relations. Nothing in this quality standard should be interpreted in a way that would be inconsistent with compliance with those duties. We wondered whether this NICE Quality Standard Document will be able to pass/fail the Equality Impact Assessment according to the NICE equality policy if it fails to recommend parity for adults with eating disorders compared to children and young people with eating disorders? We propose that the quality standards document, in its structure and layout, should avoid having different sections for adults and young people/children unless there is a clear evidence-base for different waiting times for the age groups.

99	RD-UK: The Association of Consultants and Specialists in Restorative Dentistry	1	The earliest opportunity to diagnose eating disorder might be during a visit to the family dentist and this has not been considered anywhere in the document. Regular vomiting and restrictive diets high in fruit juices and diet drinks can cause erosion of enamel and subsequently dentine. In the very earliest stages this would not be obvious to the patient, family members or doctors. The characteristic glossy appearance of early enamel erosion might, however be spotted by the dentist under the bright light and close inspection conditions of dental examination. There is potential, therefore, for early diagnosis by primary care dental practitioners. Further, if tooth wear progresses to the extent that it requires treatment, patients may be referred to a Consultant in Restorative Dentistry. Integration of primary care and Specialist dental centres/Dental Hospitals with other healthcare providers involved in management would be of great benefit. Training of primary care and specialist practitioners in how to raise concerns sensitively with patients and how to expedite onward referral when deemed necessary would be extremely useful. Tooth wear is generally preventable by dietary advice including avoidance of acidic drinks and cessation of vomiting. It is recognised that this patient cohort may be unwilling to co-operate and it might be useful to work in partnership with other healthcare professionals and the patients to find practical ways of preventing erosive damage. Once acidic wear has reached the dentine layer in the tooth, it progresses more rapidly and can end in destruction of the entire dentition. Patients can be left with a large burden of treatment and cost to endure which can be extremely distressing and difficult to manage. Especially as the appearance of the teeth can become very unsightly with destructive wear.
100	University of Sheffield	1	This statement should have the words ‘evidence-based’ or ‘effective’ placed before ‘treatment’
101	University of Sheffield	1	Almost all of the detail here is about children and younger people (drawn from the A&WT standards for this age group. However, there is almost nothing about adults of any age. This is clearly discriminatory, as the quality statement is about all patients of all ages.

102	Autistica	2	To ensure treatment options are tailored appropriately to people's needs, this quality statement should explicitly account for the significant proportion of people with an eating disorder, particularly anorexia nervosa, who are autistic. Whether or not a person is autistic is likely to impact on the nature of that person's eating disorder and their response to psychological treatments. **A significant proportion of people with anorexia nervosa are autistic** Studies consistently show that between 20 and 30% of women with anorexia nervosa are autistic.[i] Furthermore there is strong evidence that these figures represent the presence of 'true autism' and not a phenocopy resulting from anxiety or starvation.[ii,iii] The autistic characteristics of women with AN have been found to predate their eating disorder[iv,v] and the prevalence of autism remains high in samples of women who have restored body weight after recovering from anorexia nervosa.[vi] **Under existing practice autistic people with eating disorders experience particularly poor outcomes** The lack of recognition of autistic people within this quality standard is deeply concerning, as there is evidence that eating disorder services are currently failing to meet autistic people's needs. Amongst patients with anorexia nervosa, autistic people have been found to benefit the least from existing interventions and care pathways[vii,viii] and have the worst outcomes, with particularly low rates of recovery and levels of functioning.[ix] A growing body of evidence is demonstrating the importance of adapting mental health interventions to better suit autistic people.[x,xi,xii,xiii,xiv] As it stands, clinicians following this quality standard (and other NICE guidance on eating disorders) will have no indication that they may need to make adaptations for a significant and distinct proportion of their patients.
103	BEAT	2	The 'Process' part of the 'Quality measures' section of this statement should include "*(and their parents or carer as appropriate)*" to bring it in line with the 'Rationale' section and the 'What the quality statement means for different audiences' section of this quality statement.
104	BEAT	2	This statement should include at least one 'Outcome' within the 'Quality measures' section.

105	British Society of Gastroenterology & Royal College of Physicians	2	This is an extremely soft criterion. Fundamentally the standard makes no reference to what constitutes a ‘discussion’. On the one hand, this could simply involve listing a series of treatment modalities that might be available, without any meaningful explanation. Alternatively it could equally indicate a detailed assessment, formulation and recommendations for a program of treatment. Both could equally count as “a discussion” and therefore, the term provides practically no useful quality data. A much closer definition is required. The same should apply to the statement about “service providers”. All that is required of the service provider is to ensure that a pathway is in place for people with an ED to have “a discussion” with a health care professional. There is no definition of what type of healthcare professional is meant, or what the “discussion” entails. The statement that, “healthcare professionals should have training in discussing these options and supervision with monitoring of competency” is laudable but the quality statement does not explain how this should occur or what counts as “competent”. Taken at face value, it appears that the only requirement is that the healthcare professional has had some training about discussing of options, rather than actually delivering any meaningful care. The wording needs to be much more precise. As an absolute minimum, the data set should include the number of patients who actually take up some form of treatment rather than simply discuss it. Finally the recognition that patients with high risk anorexia nervosa may have avoidant behaviours highlights the inadequacy of this measure. A poorly organised service that fails to ensure that patients attend and does not deal with avoidant behaviour, might in theory have extremely good statistics, because the few patients that it does manage to see all have a “discussion” even if they subsequently succeed in avoiding treatment. Simply concentrating on the discussion of treatment is a totally inadequate measurement In anorexia nervosa it would be much more meaningful to document how many patients attend, what treatment they are offered, the number of patients who undergo inpatient treatment and the use of mental health legislation such as compulsory treatment orders.

106	Association for Family Therapy and Systemic Practice UK	2	We are very concerned by the added statement which appears in QS2 and QS4: "Family therapy is not an appropriate psychological treatment option for children and young people who have been abused by family members or those who are in care." Although we were not asked to comment on QS 2 and 4 this is a significant alternation from the previous version of the quality standards and so we feel it is pertinent to comment. This statement reflects a very naïve understanding of family therapy, and indeed families. As all family therapists will have understood through their training, family composition is very varied and not exclusively focused on a biological nuclear family. The above statement suggests that family therapy should be restricted only to families of origin, and only where parents are supportive. Family therapists have specific skills in working with conflict, abuse, blame and difficult communication within families and in paying attention to and addressing the unequal power relationships in families, with or without abusive situations. Family therapy can take place with subsystems of a family group, and even with individuals. Our membership have raised the following issues with this statement: • All psychotherapies can have deleterious effects. If NICE is going to start issuing cautions, it needs to do this with all forms of treatment in an even-handed way. • To proscribe family therapy for all children or young people that have experienced abuse from family members or who are looked after rides roughshod over any assessment that might be made about attachments between young people and their carers. Examples that make a nonsense of this statement include: ○ young people abused by a grandparent or aunt/uncle but who have loving parents who believed the child when they disclosed and did what was necessary to protect them, ○ young people on a care order or SGO currently being looked after by family members and receiving 'good enough' care. • If this statement stands, it will preclude young people having access to a modality with a good evidence base with BN, and also reduce patient choice.

			• There are certainly instances where seeing a child or young person with one or more of their carers can perpetuate an emotionally abusive situation, or at least inflict unnecessary pain, because those carers will never respond in the emotionally-attuned way that is longed-for. A carefully worded caution to the effect that family approaches to treatment should only be offered where it is clear that the child or young person will not be re-abused or emotionally harmed by offering conjoint therapy is not unreasonable. This is always true, and it is acceptable to state it. But the wording matters. • Family Therapy is designed to address difficulties in communication and relationships– if communication and relationships are easy, there is often less need for family therapy as an intervention – so excluding situations which might be seen to make communication and relationships difficult is actually excluding a context where family therapy can be at its most powerful and effective as a psychological therapy. • At the very start of foundation courses in family therapy there is always a question: “What is a family?” – the family is a system of communication and relationships that the family themselves determine membership of, and whose goals are to thrive as a such a system – so families where the children are looked after definitely qualify; and families where an abusive parent/ family member is no longer welcome can still access, utilize and benefit from family therapy without (and rarely but possibly with) the involvement of the perpetrator. In practice with all families, the membership of sessions are carefully negotiated and agreed with the family members seeking input. There are also numerous approaches methods and techniques within the family therapy canon which can help families process and understand the ramifications/ impact of any abuse in the absence of the perpetrator (as well as techniques aimed at supporting perpetrators accepting responsibility for their behaviour and its impact - though usually this is held separate from the person they have abused). We feel that this statement as it stands is prejudicial against children and young people who are being looked after, and children and young people who have experienced familial abuse. Any statement of caution should be about highlighting that there are some circumstances where psychological therapies may replicate abusive and unequal power relationships in families and this should be included in clinical

			assessment and discussions with children and young people, and their families and carers about their wishes concerning psychological therapy. The caution should not only be applied to family therapy as it can also be a problematic issue in any treatment; family therapists, at least, have received training and supervised experience in identifying and negotiating these issues, in partnership with the child or young person and family members / carers. It also should not be only applied to treatment of eating disorders since it is not the eating disorder context, per se, in which clinicians should exercise competent professional judgement and discuss issues effectively with the people concerned. The same concerns could be relevant in any expression of distress in the relationships between children and young people and the adults who care for them, and is the very reason that family therapists have ample training in and reflection upon how to ethically manage these power dynamics to first do no harm, and to secondly improve outcomes for the people and relationships who are the focus of therapy. We request that the statement, as it stands, is removed.

107	NHSE-CAHMS	2	So although NICE is saying only comment on QS1, 5 & 6, in this consultation, they have made a significant change to the recommendations for children with bulimia (old QS3, new QS4), hence we have reviewed the statement number 2/4. The restrictions on old Q3. and new Q4 that Diana has identified don't appreciate these not-all-that-subtle subtleties, and may perversely (for a NICE set of standards) prevent service users getting the best care possible. The way it's written reflects a conceptualisation of family therapy as only for biological families and only supportive biological parents, which misses the point, somewhat. The evidence base is that work with the family about changing patterns, working on difficulties or work with parents/ carers, which may be psychoeducation or coaching for how they can support the young person to eat more regularly is required to assist recovery. Clearly if a young person is in care the main focus would be with their careers. There may well be family work of some description needed to resolve whatever problems lead to them being in care/ to skill up parents to manage their needs in order to return home. If the young person has been abused by a family member they may need work together with the non-abusing parent to repair the relationship but should not be expected to attend family sessions with their abuser present unless as part of a very specific and carefully planned intervention (which would not be to do the ED per se)
108	Faculty of Dental Surgery of the Royal College of Surgeons of England	2	Healthcare professionals should include Dentists

109	NHSE- Clinical Policy and Mental Health Strategy Delivery and Information	2	Could we emphasis joint decision making – rephrase to state: Patient choice and joint decision making is important in these discussions
110	NHSE- Clinical Policy and Mental Health Strategy Delivery and Information	2	Add reference to the Mental Health Services Data Set (MHSDS)
111	British Society of Gastroenterology & Royal College of Physicians	3	The BSG has no particular concerns over the psychological treatments offered for BED. The data criterion specifies "relapse rates" for people with binge eating disorder but does not specify over what period of time. Ideally there would be a short term measure, for example remission over 4-6 months, but also a long term measure such as being disease free at 2 years. In contrast to the two earlier standards, the binge eating disorder recommendations are extremely prescriptive and almost demand too much detail.
112	Faculty of Dental Surgery of the Royal College of Surgeons of England	3	Healthcare professionals should include Dentists
113	Royal College of Psychiatrists	3	We agree with this quality statement. However, there will be resource implications for commissioners: in many areas, specialist eating disorder services have been commissioned only for 'moderate and severe cases' and binge-eating disorders are often not included in the service specifications.

114	Royal College of Psychiatrists	4	The current wording of this quality standard is not consistent with Statement 2: ‘Discussion about psychological treatment options’, or with the NICE guidance, which also includes the statement ‘If FT-BN is unacceptable, contraindicated or ineffective, consider individual eating-disorder-focused cognitive behavioural therapy (CBT-ED) for children and young people with bulimia nervosa.’ It would be helpful to reword the quality statement to ensure consistency with the NICE guidelines.

115	Association for Family Therapy and Systemic Practice UK	4	We are very concerned by the added statement which appears in QS2 and QS4: "Family therapy is not an appropriate psychological treatment option for children and young people who have been abused by family members or those who are in care." Although we were not asked to comment on QS 2 and 4 this is a significant alternation from the previous version of the quality standards and so we feel it is pertinent to comment. This statement reflects a very naïve understanding of family therapy, and indeed families. As all family therapists will have understood through their training, family composition is very varied and not exclusively focused on a biological nuclear family. The above statement suggests that family therapy should be restricted only to families of origin, and only where parents are supportive. Family therapists have specific skills in working with conflict, abuse, blame and difficult communication within families and in paying attention to and addressing the unequal power relationships in families, with or without abusive situations. Family therapy can take place with subsystems of a family group, and even with individuals. Our membership have raised the following issues with this statement: • All psychotherapies can have deleterious effects. If NICE is going to start issuing cautions, it needs to do this with all forms of treatment in an even-handed way. • To proscribe family therapy for all children or young people that have experienced abuse from family members or who are looked after rides roughshod over any assessment that might be made about attachments between young people and their carers. Examples that make a nonsense of this statement include: ○ young people abused by a grandparent or aunt/uncle but who have loving parents who believed the child when they disclosed and did what was necessary to protect them, ○ young people on a care order or SGO currently being looked after by family members and receiving 'good enough' care. • If this statement stands, it will preclude young people having access to a modality with a good evidence base with BN, and also reduce patient choice.

			• There are certainly instances where seeing a child or young person with one or more of their carers can perpetuate an emotionally abusive situation, or at least inflict unnecessary pain, because those carers will never respond in the emotionally-attuned way that is longed-for. A carefully worded caution to the effect that family approaches to treatment should only be offered where it is clear that the child or young person will not be re-abused or emotionally harmed by offering conjoint therapy is not unreasonable. This is always true, and it is acceptable to state it. But the wording matters. • Family Therapy is designed to address difficulties in communication and relationships– if communication and relationships are easy, there is often less need for family therapy as an intervention – so excluding situations which might be seen to make communication and relationships difficult is actually excluding a context where family therapy can be at its most powerful and effective as a psychological therapy. • At the very start of foundation courses in family therapy there is always a question: “What is a family?” – the family is a system of communication and relationships that the family themselves determine membership of, and whose goals are to thrive as a such a system – so families where the children are looked after definitely qualify; and families where an abusive parent/ family member is no longer welcome can still access, utilize and benefit from family therapy without (and rarely but possibly with) the involvement of the perpetrator. In practice with all families, the membership of sessions are carefully negotiated and agreed with the family members seeking input. There are also numerous approaches methods and techniques within the family therapy canon which can help families process and understand the ramifications/ impact of any abuse in the absence of the perpetrator (as well as techniques aimed at supporting perpetrators accepting responsibility for their behaviour and its impact - though usually this is held separate from the person they have abused). We feel that this statement as it stands is prejudicial against children and young people who are being looked after, and children and young people who have experienced familial abuse. Any statement of caution should be about highlighting that there are some circumstances where psychological therapies may replicate abusive and unequal power relationships in families and this should be included in clinical

			assessment and discussions with children and young people, and their families and carers about their wishes concerning psychological therapy. The caution should not only be applied to family therapy as it can also be a problematic issue in any treatment; family therapists, at least, have received training and supervised experience in identifying and negotiating these issues, in partnership with the child or young person and family members / carers. It also should not be only applied to treatment of eating disorders since it is not the eating disorder context, per se, in which clinicians should exercise competent professional judgement and discuss issues effectively with the people concerned. The same concerns could be relevant in any expression of distress in the relationships between children and young people and the adults who care for them, and is the very reason that family therapists have ample training in and reflection upon how to ethically manage these power dynamics to first do no harm, and to secondly improve outcomes for the people and relationships who are the focus of therapy. We request that the statement, as it stands, is removed.
116	BEAT	4	The addition of the measurement of frequency of purging behaviour to the measurement of frequency of bingeing behaviour is an improvement on the previous draft of this quality statement. However, some children and young people with bulimia nervosa may experience ‘diagnostic crossover’ to a diagnosis of anorexia nervosa (or Atypical anorexia nervosa), through the adoption of non-purging forms of compensatory behaviours. It appears that this would not be covered by the current quality measures, although this may depend on the definition used for ‘recovery’ in part c).
117	BEAT	4	Within the paragraph for ‘Healthcare professionals’ the use of “*if appropriate*” appears to be an error, since the statement concerns the offer of family therapy.
118	British Society of Gastroenterology & Royal College of Physicians	4	The BSG has no issues with this as a treatment modality. Once again, however, the statement is directed primarily at young people and there is no attempt to measure the quality of care for older patients with bulimia nervosa. It is a recurring criticism of this quality statement that is primarily written for younger people and only includes adults as an afterthought. This is completely contradicts the principles underpinning the quality statements, contained in the supporting documents issued by NICE. As a minimum the wording should be changed to at least include adults more specifically.

119	NHSE-CAHMS	4	So although NICE is saying only comment on QS1, 5 & 6, in this consultation, they have made a significant change to the recommendations for children with bulimia (old QS3, new QS4), hence we have reviewed the statement number 2/4. The restrictions on old Q3. and new Q4 that Diana has identified don't appreciate these not-all-that-subtle subtleties, and may perversely (for a NICE set of standards) prevent service users getting the best care possible. The way it's written reflects a conceptualisation of family therapy as only for biological families and only supportive biological parents, which misses the point, somewhat. The evidence base is that work with the family about changing patterns, working on difficulties or work with parents/ carers, which may be psychoeducation or coaching for how they can support the young person to eat more regularly is required to assist recovery. Clearly if a young person is in care the main focus would be with their careers. There may well be family work of some description needed to resolve whatever problems lead to them being in care/ to skill up parents to manage their needs in order to return home. If the young person has been abused by a family member they may need work together with the non-abusing parent to repair the relationship but should not be expected to attend family sessions with their abuser present unless as part of a very specific and carefully planned intervention (which would not be to do the ED per se)
120	Faculty of Dental Surgery of the Royal College of Surgeons of England	4	The examination questionnaire should include Dental Questions too P16 as in Statements 1,2 and 3 P17 could include discussions around self-perceived body issues including the smile and teeth

121	Oxford Health NHS Foundation Trust	4	While we accept that the request for this 2nd consultation is only for statement 1, 5 and 6, we want to suggest again that statement 4 needs to be amended in line with the NICE guidelines. Statement 4 reads: *Children and young people with bulimia nervosa are offered bulimia-nervosa-focused family therapy (FT-BN).* We suggest that the following statement should be added: *where acceptable and indicated. If FT-BN is unacceptable, contraindicated or ineffective, CBT-Ed should be offered.* Considerable investment in staff training and resources needs to be made for this standard to be achieved
122	BEAT	5	We are pleased to see that the QSAC has responded to the recommendation of the Parliamentary Health Services Ombudsman (PHSO) and the feedback from Beat and other stakeholders, which called for the quality standard to address the topic of coordination of care. We welcome the inclusion of quality statements 5 and 6. “Statement 5 should ensure that the care of people with anorexia is better co-ordinated. The comment "Particular care should be taken when more than one healthcare service is involved...." is particularly important to me as we were passed from one department to another when we were trying to access care for our daughter and no-one seemed to take responsibility for her treatment. Better communication between services, with a Care Programme would seem to be an excellent step forward.” (Margaret). “When she [my daughter] moved from home to university it would have been really useful for her to have a risk assessment and a care plan which continued during her studies. She received very little psychological support at university and we had to pay for private counselling when she needed it.” (Margaret) “One of the notable strengths of these new statements is that they demonstrate a more directed focus on key points for quality improvement around eating disorders for both "new" or first-episode ED patients and for patients with longer-term, more severe and/or "intractable" EDs” (Emma)

123	BEAT	5	We welcome the QSACs decision to create two separate statements on coordination of care, as the two statements cover related but distinct aspects of the coordination of care. Some experiences could be left out if an attempt was made to address this topic with a single quality statement. “The explicit separation of the two key areas for quality improvement -- where more than once agency/service is involved (QS5) versus moving between services (QS6) is a notable strength since, although the points (and risks) covered in each statement are similar, the elision of the two would in my opinion impoverish the document and frustrate the intentions of both. I would stress that although NICE emphasises most QS documents will contain only five points, I think at the very least these two quality statements should remain discrete, not least because they encompass so many points of clinical risk -- specificity is paramount.” (Emma)
124	BEAT	5	Commenting in support of the inclusion of these statements another volunteer recounted her experiences of poor coordination of care and the risks associated with this: “Speaking as someone under an eating disorder service and a specialist team for my [Comorbidity] on numerous occasions I have experienced complications due to a lack of coordination of care. It is very easy for things to be missed or unresolved when more than one service is involved, as assumptions are often made that another service is dealing with an issue. This in itself can have lethal results but, at best, it can lead to delays in treatment and feelings of anxiety and mistrust in the patient. Alongside the physical risks increased by a lack of poor coordination of services, psychologically it can potentially be equally dangerous. I have experienced receiving mixed, even contradictory, messages from different teams. I also fear a lack of coordination and adequate communication leaves space for an eating disorder to “act as a messenger” between services, which undoubtedly increases the risk of information being skewed or not communicated. Potentially, the perfect conditions for the manipulative side of an eating disorder to emerge can be created, which in many different ways could have disastrous results…transitions between services can be another "opportunity" for the manipulative or dishonest side of an eating disorder to emerge if appropriate continuity of care measures are not securely in place” (Lara)

125	BEAT	5	Another volunteer stressed the importance of GPs being involved in care planning to ensure consistent messages, management approaches and clarity about clinical responsibilities: “In relation to statements 5 and 6, I feel that it is important to emphasise that good co-ordination of services for eating disorders is most likely to be achieved where professionals from different services are conveying the same messages to patients and this requires a basic understanding of eating disorders. In my experience, I have been supported 'intensively in the community' which has meant that there has been a significant amount of support required from primary services. Whilst logistically this has been managed well, there is a clear disparity in the understanding of practitioners in this area and I have often been told that the physical monitoring (ECG, blood tests, weight) is excessive. Moreover, I have rarely known GPs to attend CPA meetings where these difficulties could be addressed and a more consistent approach could be developed.” (Someiia)
126	British Society of Gastroenterology & Royal College of Physicians	5	The aim of this statement is well accepted. Patients can be lost when they transfer between different services (‘mind the gap’). The principal is well accepted but whether a limited audit of patient notes will really alter this is debatable.
127	Leicestershire Adult Eating Disorders Service	5	We agree with the statement that care across services should be co-ordinated.
128	Leicestershire Adult Eating Disorders Service	5	We would be able to measure this in our service.
129	NHSE-Primary Care Team	5	Statement describes how the delivery of coordinated services will be provided by means of a care plan appropriately.
130	Oxford Health NHS Foundation Trust	5	Data collection is feasible. Data collection within inpatient services (especially in CAMHS ED) needs further development.

131	Royal College of General Practitioners	5	This statement does not go far enough. It must explicitly state that the care plan is shared with all partners but in particular the patient’s GP. From the report about failings in care, it was obvious that communication between primary care and secondary care specialist services was poor. A care plan must be shared with all parties involved and the care coordinator must check that all parties are undertaking their required roles and responsibilities. It should also explicitly state what is expected and who will do this. There should be a contact number for the care coordinator on the care plan to allow relevant parties to update or ask questions.
132	Royal College of General Practitioners	5	Consider amending “Numerator – the number in the denominator who have a care plan that explains how the services will work together” to “Numerator – the number in the denominator who have a care plan that explains how the services will work together to help the individual patient”. It is important that the care plan is a personalised care plan.
133	Royal College of Psychiatrists	5	The draft quality standards states: a) Proportion of people with an eating disorder who are supported by more than one service who relapse. It is unclear how the focus on ‘relapse’ is a helpful measure of the outcome of statement 5. People requiring input from more than one service are likely to have complex comorbidity and a chronic condition. They are more likely to relapse irrespective of whether they ‘are being supported by more than one service’ and whether they ‘have care plan that explains how the services will work together’. Having support from various services and a care plan in place may (or may not) avoid relapse.

134	NHSE-Eating disorders Advisory Group	5	Local data collection, for example, contracts and service specifications are unlikely to be sufficiently detailed to specify joint working arrangements between services. Collecting information about joint care plans by means of a local audit of patient records will be extremely time-consuming and is unlikely to be feasible unless specific resources are made available. Following patients up to establish how many relapse will be even more difficult. The requirement that care plans should specify in advance the arrangements for urgent or emergency admission (including indications, procedure and location) is unrealistic. Due to the shortage of eating disorders beds nationally, urgent admission usually involves ringing round the country to locate a bed and the patent being admitted wherever there is a bed available. It is clinically inappropriate to specify in advance the objectives and outcomes for inpatient treatment and how the person with the eating disorder will be discharged. These decisions should be made at the time of admission/discharge, in the light of the patient's needs and the clinical presentation.
135	Oxford Health NHS Foundation Trust	5	The draft quality standards states: a) Proportion of people with an eating disorder who are supported by more than one service who relapse. It is unclear how the focus on 'relapse' is a helpful measure of the outcome of statement 5. The reality is that some people relapse irrespective of whether they 'are being supported by more than one service' and whether they 'have care plan that explains how the services will work together'. Having support from various services and a care plan in place may (or may not) avoid relapse.
136	Oxford Health NHS Foundation Trust	5	The draft quality standards states: b) Proportion of people with an eating disorder who are supported by more than one service who continue to engage with services using their care plan. It is unclear whether the focus on 'engagement' is the best way of measuring the outcomes of statement 5. (Dis)engagement may or may not be dependent on whether people 'are being supported by more than one service' and whether they 'have care plan that explains how the services will work together'. Having support from various services and a care plan in place may (or may not) ensure engagement.

137	Oxford Health NHS Foundation Trust	5	The process statements a and b appear to be more helpful outcome measures than the outcome statements a and b. We wonder whether the process statements could be used as outcome measures? Please see below. Process a) Proportion of people with an eating disorder who are supported by more than one service who have a care plan that explains how the services will work together. b) Proportion of people with an eating disorder being supported by more than one service who have CPA meetings to discuss their care plans. versus Outcome a) Proportion of people with an eating disorder who are supported by more than one service who relapse. b) Proportion of people with an eating disorder who are supported by more than one service who continue to engage with services using their care plan.
138	Faculty of Dental Surgery of the Royal College of Surgeons of England	5	Structure and process needs to include Dental in an MDT
139	NHSE- Clinical Policy and Mental Health Strategy Delivery and Information	5	Comment on including '…separate healthcare services treating a comorbidity...' For CYP the expectation is that the community eating disorder teams treat the eating disorder as well as any co-morbidity. This came across strongly from CYP and parents who expressed their frustration with elements of their need/presentation being treated by different services. This was also highlighted in PHSO.
140	NHSE- Clinical Policy and Mental Health Strategy Delivery and Information	5	Note – I'm not sure we can adapt this text but a key issue being reported at the moment is the need for a discharge date to be agreed prior to or at the start of admission - could the final bullet be amended to state 'how **and when** the person with the eating disorder...'

141	RD-UK: The Association of Consultants and Specialists in Restorative Dentistry	5	The earliest opportunity to diagnose eating disorder might be during a visit to the family dentist and this has not been considered anywhere in the document. Regular vomiting and restrictive diets high in fruit juices and diet drinks can cause erosion of enamel and subsequently dentine. In the very earliest stages this would not be obvious to the patient, family members or doctors. The characteristic glossy appearance of early enamel erosion might, however be spotted by the dentist under the bright light and close inspection conditions of dental examination. There is potential, therefore, for early diagnosis by primary care dental practitioners. Further, if tooth wear progresses to the extent that it requires treatment, patients may be referred to a Consultant in Restorative Dentistry. Integration of primary care and Specialist dental centres/Dental Hospitals with other healthcare providers involved in management would be of great benefit. Training of primary care and specialist practitioners in how to raise concerns sensitively with patients and how to expedite onward referral when deemed necessary would be extremely useful. Tooth wear is generally preventable by dietary advice including avoidance of acidic drinks and cessation of vomiting. It is recognised that this patient cohort may be unwilling to co-operate and it might be useful to work in partnership with other healthcare professionals and the patients to find practical ways of preventing erosive damage. Once acidic wear has reached the dentine layer in the tooth, it progresses more rapidly and can end in destruction of the entire dentition. Patients can be left with a large burden of treatment and cost to endure which can be extremely distressing and difficult to manage. Especially as the appearance of the teeth can become very unsightly with destructive wear.

142	Royal College of Psychiatrists	5	The draft quality standards states: b) Proportion of people with an eating disorder who are supported by more than one service who continue to engage with services using their care plan. It is unclear whether the focus on ‘engagement’ is the best way of measuring the outcomes of statement 5. (Dis)engagement may or may not be dependent on whether people ‘are being supported by more than one service’ and whether they ‘have care plan that explains how the services will work together’. Having support from various services and a care plan in place may (or may not) ensure engagement.
143	BEAT	6	We are pleased to see that the QSAC has responded to the recommendation of the Parliamentary Health Services Ombudsman (PHSO) and the feedback from Beat and other stakeholders, which called for the quality standard to address the topic of coordination of care. We welcome the inclusion of quality statements 5 and 6. “Statement 5 should ensure that the care of people with anorexia is better co-ordinated. The comment "Particular care should be taken when more than one healthcare service is involved...." is particularly important to me as we were passed from one department to another when we were trying to access care for our daughter and no-one seemed to take responsibility for her treatment. Better communication between services, with a Care Programme would seem to be an excellent step forward.” (Margaret). “When she [my daughter] moved from home to university it would have been really useful for her to have a risk assessment and a care plan which continued during her studies. She received very little psychological support at university and we had to pay for private counselling when she needed it.” (Margaret) “One of the notable strengths of these new statements is that they demonstrate a more directed focus on key points for quality improvement around eating disorders for both "new" or first-episode ED patients and for patients with longer-term, more severe and/or "intractable" EDs” (Emma)

144	BEAT	6	We welcome the QSACs decision to create two separate statements on coordination of care, as the two statements cover related but distinct aspects of the coordination of care. Some experiences could be left out if an attempt was made to address this topic with a single quality statement. “The explicit separation of the two key areas for quality improvement -- where more than once agency/service is involved (QS5) versus moving between services (QS6) is a notable strength since, although the points (and risks) covered in each statement are similar, the elision of the two would in my opinion impoverish the document and frustrate the intentions of both. I would stress that although NICE emphasises most QS documents will contain only five points, I think at the very least these two quality statements should remain discrete, not least because they encompass so many points of clinical risk -- specificity is paramount.” (Emma)
145	BEAT	6	Commenting in support of the inclusion of these statements another volunteer recounted her experiences of poor coordination of care and the risks associated with this: “Speaking as someone under an eating disorder service and a specialist team for my [Comorbidity] on numerous occasions I have experienced complications due to a lack of coordination of care. It is very easy for things to be missed or unresolved when more than one service is involved, as assumptions are often made that another service is dealing with an issue. This in itself can have lethal results but, at best, it can lead to delays in treatment and feelings of anxiety and mistrust in the patient. Alongside the physical risks increased by a lack of poor coordination of services, psychologically it can potentially be equally dangerous. I have experienced receiving mixed, even contradictory, messages from different teams. I also fear a lack of coordination and adequate communication leaves space for an eating disorder to “act as a messenger” between services, which undoubtedly increases the risk of information being skewed or not communicated. Potentially, the perfect conditions for the manipulative side of an eating disorder to emerge can be created, which in many different ways could have disastrous results…transitions between services can be another "opportunity" for the manipulative or dishonest side of an eating disorder to emerge if appropriate continuity of care measures are not securely in place” (Lara)

146	BEAT	6	Another volunteer stressed the importance of GPs being involved in care planning to ensure consistent messages, management approaches and clarity about clinical responsibilities: “In relation to statements 5 and 6, I feel that it is important to emphasise that good co-ordination of services for eating disorders is most likely to be achieved where professionals from different services are conveying the same messages to patients and this requires a basic understanding of eating disorders. In my experience, I have been supported 'intensively in the community' which has meant that there has been a significant amount of support required from primary services. Whilst logistically this has been managed well, there is a clear disparity in the understanding of practitioners in this area and I have often been told that the physical monitoring (ECG, blood tests, weight) is excessive. Moreover, I have rarely known GPs to attend CPA meetings where these difficulties could be addressed and a more consistent approach could be developed.” (Someiia)
147	BEAT	6	The quality statement only refers to risks being assessed whereas the ‘Rationale’, ‘Quality measures’ (with the exception of the ‘Process’ section) and ‘What the quality statement means for different audiences’ sections refer to monitoring. Could the statement be reworded to clarify that monitoring is expected across the period of transition between services rather than just a risk assessment at a single point in time?
148	BEAT	6	In the case of people moving between geographical areas (including students) the transition protocols referred to should include home-based services (such as their GP and/or current eating disorders service) contacting the service/s in the person’s term-time area to arrange for an appointment to take place soon after arrival. It would be useful for the quality standard to refer to/signpost readers to the Royal College of Psychiatrists publication CR208 ‘Managing transitions when the patient has an eating disorder: Guidance for good practice’.
149	BEAT	6	Guidance should be provided about the time-period denoted by the terms ‘transition’, ‘on transfer’ and ‘moving between services’. Referring to NICE Guideline NG43 may help with this.
150	BEAT	6	The definition of a ‘care plan’ should be included here as it was for Quality statement 5. This is particularly important because it reminds the reader of the importance of a care plan being developed in collaboration with the patient and their parents or carers (if appropriate).
151	BEAT	6	The ‘Outcome’ is stated as ‘Service user experience of eating disorder services’, but the ‘Data source’ for this is suggested to be “local audits on care plans”. It would be suitable to suggest ‘local patient surveys’.

152	British Society of Gastroenterology & Royal College of Physicians	6	Transitioning is recognised to be very important and the measurement of the number of patients with a care plan is probably achievable. The term "Service user experience of eating disorders services", is again extremely vague and the quality statement would be greatly improved if more specific measures were outlined. In general the single measure that would improve quality of care most effectively, would be a serious attempt to implement the measures outlined in Marsipan and Junior Marsipan. This measure alone would answer much of the criticism of the earlier part of the standards. The absence of a quality statement relating to anorexia nervosa is a huge omission. This is the group of patients who have the highest chance of dying if care is inadequate. It seems slightly unusual that very specific quality statements have been made about binge eating disorder and bulimia nervosa, which have a lower mortality rate, but no meaningful statement has been made about anorexia nervosa.
153	Leicestershire Adult Eating Disorders Service	6	We are confused by the line 'Healthcare professionals communicate the care plan at a recorded meeting with all the services involved. Does this mean that we would be expected to have a face to face or even skype type meeting for every patient we transition. This would not be feasible, Also, not all patients are of the complexity to require a face to face meeting. If this line means that the current team meet, do a care plan and communicate the care plan to other services that is feasible. This line needs to be more clear.
154	Leicestershire Adult Eating Disorders Service	6	When we transition patients e.g students to other geographical areas, we may have our own transition protocol, but we cannot influence the protocol at the other end. Hence if you are measuring this, we can easily show you our protocol, but it may not have any effect on the care the care the student receives at University.
155	Leicestershire Adult Eating Disorders Service	6	One way to make transition smoother for uni students would be to allow 2 GPs to hold the patient at the same time. At present, what prevents effective transition is that the patient cannot even be discussed with the receiving ED team until they are open to the local GP. This means that the local ED team only hear about the patient once they are already arrived at University. This change would greatly improve our ability to safely transition students to university.

156	NHSE-Primary Care Team	6	Statement address risk assessment and transition protocols to ensure care does not fall in between the different services and the services will need to ensure liaison as per quality standards and the CPA.
157	Oxford Health NHS Foundation Trust	6	There are resource implications for safe risk management in the transition between CAMHS and adult services, as waiting times for starting treatment within adult services are unacceptably long.
158	Royal College of General Practitioners	6	Monitoring this quality statement focuses on structure and process to improve coordinated care when moving between services. It would be helpful to specifically mention management of boundary disputes between services when neither service will take responsibility for a patient or when one services believes the other service should take over responsibility.
159	Royal College of Psychiatrists	6	The heading of this quality standard is 'Coordinated care when moving between services, but the quality statement only focuses on risk assessment: 'People with an eating disorder who are moving between services have their risks assessed'. We propose that risk assessment and management should be an integral part of eating disorder treatment throughout the care pathway, and not just during transition.
160	Royal College of Psychiatrists	6	It may also be helpful to include the Parliamentary Ombudsman's recommendation: to conduct and learn from serious incident investigations, including those that are complex and cross organisational boundaries – as these should inform the need for improving shared care working protocols.
161	NHSE-Eating disorders Advisory Group	6	The importance of well-managed transitions between services cannot be over-emphasised. This statement is in line with recently published guidance from the Royal College of Psychiatrists, which should be cited (Managing Transitions When the Patient has an Eating Disorder, College Report 208, 2017). It is difficult to see how service user experience of eating disorder services can be measured through "Local data collection, for example, local audits on care plans".
162	Oxford Health NHS Foundation Trust	6	The statement reads: People with an eating disorder who are moving between services have their risks assessed. We suggest that risk management is referred to in the standard rather than purely risk assessment and monitoring.

163	Oxford Health NHS Foundation Trust	6	The draft document suggests: Proportion of people with an eating disorder who are moving between services who have a care plan that includes a risk assessment on transfer. We suggest rewording to: Proportion of people with an eating disorder who are moving between services who have a care plan that ensures that processes are in place for risk management (including assessment and monitoring).
164	Oxford Health NHS Foundation Trust	6	Similarly, we suggest rewording of the following: Numerator – the number in the denominator who have a care plan that includes a risk assessment on transfer. To Numerator – the number in the denominator who have a care plan that ensures that processes are in place for risk management (including assessment and monitoring)
165	Faculty of Dental Surgery of the Royal College of Surgeons of England	6	this has little effect on dental
166	NHSE- Clinical Policy and Mental Health Strategy Delivery and Information	6	For the reasons outlined about could ‘Service user experience of eating disorder services’ be rephrased to read: 'service user’s experience of care for the treatment of an eating disorder'

Registered stakeholders who submitted comments at consultation

- Association for Family Therapy and Systemic Practice UK
- Autistica
- BEAT
- British Society of Gastroenterology
- Department of Health and Social Care
- Faculty of Dental Surgery of the Royal College of Surgeons of England
- Glasgow and Clyde Adult Eating Disorder Service (AEDS)
- Leicestershire Adult Eating Disorders Service
- NHSE-Eating Disorders Advisory Group
- NHSE-CAHMS
- NHSE-Clinical Policy and Mental Health Strategy Delivery and Information
- NHSE-Primary Care Team
- Oxford Health NHS Foundation Trust
- RD-UK: The Association of Consultants and Specialists in Restorative Dentistry
- Royal College of General Practitioners
- Royal College of Nursing
- Royal College of Paediatrics and child health

- Royal College of Psychiatrists
- Royal College of Physicians
- University of Sheffield

---

[i] Huke V, et al. (2013). Autism Spectrum Disorders in Eating Disorder Populations: A Systematic Review. European Eating Disorders Review: The Journal of the Eating Disorders Association, 21(5), 345–351.

[ii] Treasure J (2013). Coherence and other autistic spectrum traits and eating disorders: building from mechanism to treatment. The Birgit Olsson lecture. Nordic Journal of Psychiatry, 67(1), 38–42.

[iii] Westwood H, et al. (2017). Clinical evaluation of autistic symptoms in women with anorexia nervosa. Molecular Autism, 8, 12.

[iv] Mandy, W., & Tchanturia, K. (2015). Do women with eating disorders who have social and flexibility difficulties really have autism? A case series. Molecular Autism, 6, 6.

[v] Vagni, D., Moscone, D., Travaglione, S., & Cotugno, A. (2016). Using the Ritvo Autism Asperger Diagnostic Scale-Revised (RAADS-R) disentangle the heterogeneity of autistic traits in an Italian eating disorder population. Research in Autism Spectrum Disorders, 32, 143–155.

[vi] Anckarsäter, H., Hofvander, B., Billstedt, E., Gillberg, I. C., Gillberg, C., Wentz, E., & Råstam, M. (2012). The sociocommunicative deficit subgroup in anorexia nervosa: autism spectrum disorders and neurocognition in a community-based, longitudinal study. Psychological Medicine, 42(9), 1957–1967.

[vii] Tchanturia, K., Larsson, E., & Adamson, J. (2016). How anorexia nervosa patients with high and low autistic traits respond to group Cognitive Remediation Therapy. BMC Psychiatry, 16(1), 334.

[viii] Stewart, C. S., McEwen, F. S., Konstantellou, A., Eisler, I., & Simic, M. (2017). Impact of ASD Traits on Treatment Outcomes of Eating Disorders in Girls. European Eating Disorders Review: The Journal of the Eating Disorders Association.

[ix] Wentz, E., Gillberg, I. C., Anckarsäter, H., Gillberg, C., & Råstam, M. (2009). Adolescent-onset anorexia nervosa: 18-year outcome. The British Journal of Psychiatry: The Journal of Mental Science, 194(2), 168–174.

[x] Cooper K., et al. (2018). Adapting psychological therapies for autism. Research in Autism Spectrum Disorders, Vol 45: 43-50.

[xi] Autistica (2017). Our current research projects – Treating anorexia in autistic women [webpage].

[xii] Rodgers J and Ofield A (2018). Understanding, recognising and treating co-occurring anxiety in autism. Curr Dev Disord Rep, 5: 58.

[xiii] Zaboski B and Storch E (2018). Comorbid autism spectrum disorder and anxiety disorders: a brief review. Future Neurology. Vol.13(1).

[xiv] Lietz P, et al. (2018). Protocol for a systematic review: Interventions for anxiety in school-aged children with autism spectrum disorder (ASD). Campbell Collaboration.